

Meaningful Use Workgroup
Draft Transcript
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Presentation

Judy Sparrow – Office of the National Coordinator – Executive Director

Good morning, and welcome to the Meaningful Use Workgroup. This is a public hearing on the topic of patient and consumer engagement. This is a federal advisory committee, which means there will be opportunity at the end of the meeting for the public to ask questions, and we will have the materials, as well as the summary of the meeting up on the ONC Web site sometime within the week.

Just a reminder for the workgroup members to please identify yourselves when speaking. We have a large audience on the phone and on the Web. With that, I'll ask members of the workgroup to please introduce themselves, beginning on my left with Cris Ross.

Cris Ross – MinuteClinic – CIO

Good morning. I'm Cris Ross. I'm an interloper from the HIT Standards Committee and testifying later.

Neil Calman - Institute for Family Health - President & Cofounder

Neil Calman with the Institute for Family Health in New York.

Deven McGraw - Center for Democracy & Technology – Director

Deven McGraw with the Center for Democracy & Technology.

Paul Tang - Palo Alto Medical Foundation - Internist, VP & CMIO

Paul Tang, Palo Alto Medical Foundation.

George Hripcsak - Dept. of Biomedical Informatics Columbia University – Chair

George Hripcsak, Columbia University.

Christine Bechtel - National Partnership for Women & Families – VP

Christine Bechtel, National Partnership for Women and Families.

Charlene Underwood - Siemens Medical - Director, Gov. & Industry Affairs

Charlene Underwood, Siemens Healthcare.

Jim Figge – NY State DoH – Medical Director

Good morning. Jim Figge, New York State Department of Health in the Medicaid Program, Medical Director.

Josh Seidman – ONC

Josh Seidman, ONC staff.

Judy Sparrow – Office of the National Coordinator – Executive Director

Do we have any workgroup members on the telephone? Okay. With that, I'll turn it over to Dr. Tang.

Paul Tang - Palo Alto Medical Foundation - Internist, VP & CMIO

Thank you, Judy. I want to welcome everyone to this hearing, and I promise you it's going to be really a super day because the testimony, and for those who haven't read the testimony, you really need to. We're only giving the panelists five minutes to speak, but there's a lot of information in their written testimony, and you would be well rewarded by reading that.

I also want to welcome Dr. Figge from New York State Department of Health. He's going to be joining our meaningful use workgroup, so welcome. And Dr. Barr, who is from the ACP, is also joining. He's not here today, at least right now.

First, let me go over just a high level for the agenda. We have three panels, and I don't know that we've classified everybody exactly right because I think people are going to have things to say in the various other panels, but we started out with saying how is HIT technology going to play a meaningful role in the lives of everyday people. And we have panelists who have done some studies in that area and have their own views on how is it really working. How will affect their real lives? Not only the patients themselves, or the so-called designated patients, but also the caregivers, the people around them that have so much to do with their care.

In the second panel, we're going to try to get some additional information from actual evidence, in a sense, of what's going on in the real world, as these technologies move in to the real world from the patient's point of view, and conclude with our third panel trying to examine some of the policy implications of what we've heard. And, as I say, throughout all three panels, we want to look at each person's perspective on how it impacts the policy, so don't feel constrained at all, any more than the five minutes that you get to talk.

And so let me just explain how we've set all of these panels up with the panelists. They all have five minutes. They've submitted written testimony. They have five minutes to deliver their prepared remarks, and the reason we limit it that way is so we have a rich dialog with the committee members with the panelists, so there's a lot more information that'll come out in that discussion, but that's been very successful in the past, and that's why we're continuing in this way.

Let's see. We also have moderators for each panelist. For panel one, the meaningful use of HIT in real lives and patients and families, Christine Bechtel, who is one of our champion consumer leaders, is going to moderate.

Christine Bechtel - National Partnership for Women & Families – VP

Terrific. Thank you and good morning. I am really excited about this hearing today, as you can imagine, and I'm particularly excited about the first panel, not just because I get to moderate it, and I always get to open my mouth that way, but we wanted to start with this panel because we know from polling data that there's widespread consumer support for having providers use electronic health records. In a poll that we did a couple of weeks ago when we launched our campaign for better care, we found that 92% of adults age 50+ strongly want their providers to use electronic health records, and they think that because they hope it will improve communication between providers. Consumers clearly just want their doctors to talk to each other very simply, and about half of them said that they think it will reduce medical errors.

But this doesn't really shed a lot of light on how consumers themselves view their role in using health information, and so we do know, though, from some other research, and I'll give a shameless plug for next month's *Health Affairs* journal, which will focus on reinventing primary care, and we will have a piece in there that covers some of our research about what really helps consumers improve their own health outcomes. And it's clear that their two biggest pain points, and again, I want to say this to set some context for the panel. But their two biggest pain points really center on communication and coordination.

They struggle with access to care. They want partnership. They want shared decision making with their healthcare providers. And they want better and more information on how to care for themselves, and so clearly health IT can play a role as we think about how giving consumer's access to information might help them in these particular areas.

But we wanted to start with this panel because we need to understand in order to inform the meaningful use criteria for future years how is it that patients really use information in the context of their daily lives. And so we have a great panel for you today that will give perspectives on that issue based on data and research, based on observation, and based on experience, so I'm very delighted to be moderating the panel.

What I'll do is just go ahead and introduce the panelists in order that they'll speak so that we can get out of the way and hear from them. Is Regina Holliday here yet? I think she may have had some commuting challenges. When Regina gets here, we will hear from her. She has been a really terrific advocate for patients based on her own experience in the healthcare system after her husband, Fred, was diagnosed with stage four kidney cancer in late March of 2009. And she will talk about the role that access to information can play in really helping patients and families deal with health crises like this. She is a medical advocate muralist, so she uses paintbrushes to promote health reform and patients' rights to access data. And I think a number of us have seen her work on CNN, ABC, CBS, and her mural, which is called *Seventy-Three Cents*, was on the cover of BMJ in September of 2009, and we're delighted to welcome her.

Second, we're going to hear from our illustrious fellow policy committee member, Neil Calman, who actually may be first, come to think of it. Neil is a board certified family physician who has practiced in the Bronx and Manhattan for the past 30 years, so clearly since you were 9 years old. In 2002, Neil's community health center network became one of the first in the country to implement a fully integrated electronic health record and practice management system, so if Neil can do it, we can all do it. And, of course, he has been a terrific asset on the meaningful use workgroup in particular.

Next, we will hear from Dr. Chris Gibbons with Johns Hopkins University where he is an assistant professor and the associate director of the Urban Health Institute. He's also on the faculty of the School of Medicine and the School of Public Health. And the focus of his work is something very near and dear to my heart, which is the nexus of health IT and health disparities with a particular focus on consumer health informatics.

Fourth, we'll hear from Scott Mackie, who is the health practice lead for IDEO in their Boston office, which is where he helps to shape and lead a diverse range of work in the healthcare sector, including IDEO's approach to innovation, which involves using human centered approaches and applying the appropriate technology to create business ready solutions. Welcome, Scott.

Then finally, batting cleanup, we will hear from Eric Dishman. Eric is an Intel fellow and global director of health innovation and policy, which is a title we all want, I must say, for Intel's digital health group. He oversees Intel's worldwide healthcare research strategic planning and policy activities. And, importantly, he's trained as a social scientist, so he has 20 years—so again, you must have been 5 when you started—of experience in leading multidisciplinary research teams to develop new technology products by using ethnographic field work and other social science methods, which I think is really exciting, so we're delighted to welcome you all today, and let's get started first with Neil Calman.

Neil Calman - Institute for Family Health - President & Cofounder

Thanks, Christine. You're absolutely right. This is going to be an amazing day, and I'm looking forward to it, and a little nervous about being the leadoff hitter here.

Christine Bechtel - National Partnership for Women & Families – VP

You can do it.

Neil Calman - Institute for Family Health - President & Cofounder

The Institute for Family Health, which I co-founded 25 years ago, is basically a network of community health centers. We have 25 health centers. We serve an incredibly diverse population of patients. The health centers are spread over about 120 miles, and we also operate 2 family practice residency programs, so we're involved both in the service and training and do about 275,000 visits a year, so that's sort of the context.

We've been live on a completely integrated practice management and electronic health record system on Epic since 2002. Actually, our implementation started with work that we did on health disparities, and started with a view towards what could we do to sort of bridge issues of patient trust, communication between patients and providers, and to change people's experience, which, in our focus groups early on, this goes back a dozen years, in low-income, minority communities. Basically, people's experience with the healthcare system is just universally bad. Everybody had got bad stories.

I'll start by just saying that I think that from the meaningful use perspective, the patient and family engagement piece is probably the hardest to implement. I think this is the most difficult of all of the pieces of meaningful use because it's something where electronic health records can be used as a tool, but patient and family engagement doesn't fall out of electronic health records the way some of the other things do. So there really needs to be a commitment at the front end of how these systems are implemented and how they're designed to really help engage patients and families. And so let me just run through sort of a list of these things quickly, just some of the things that we've been engaged in and what we're working on, and this really is the focal point of our work on meaningful use.

First of all, how do you set up your exam rooms? We looked at the idea of these sort of computers that people nestle in their arms and think this is really not a way to bridge communication, so the set up of exam rooms with flat screen monitors that patients can watch and be a part of the documentation, be a part of the system where the computer becomes an educational tool in the exam room, I think, is critically important. There are all kinds of things that we do in sort of communication that I think we need to address, so if we're really talking about a future where patients have complete access to all of their health information, abbreviations need to go out the door completely. We no longer consider that there are joint commission, approved abbreviations and unapproved abbreviations. All abbreviations are unapproved. People have to write in language that people can understand.

And we have to teach providers to write notes in a way that patients will be reading them. Right now we write notes that are targeted towards our colleagues, but they need to be targeted towards the patients, so we need to write in language. We need to basically simplify our language. An example of this would be when doctors say that patients are noncompliant. I've challenged all of our residents, students, and everybody to give me a single thing that they feel couldn't be written in a paper record and couldn't be written in an electronic health record that a patient would be able to see. And so far, nobody has been able to stump me.

So they say things like the patient's noncompliant. How am I going to put that in the record? And I say well, ask the patient why they're not taking their medications? And they say, well, I can't afford it. I say,

why don't you put it in the medical record that the patient can't afford their medication or that their Aunt Tizzy died when she took the same medication, or find out what the real reasons are?

I can't tell a patient they're schizophrenic. Why not? When they go to the emergency room and somebody says, "What's your diagnosis," they surely should know what their medical and psychiatric diagnosis is. So we really teach people that they can document in a way that patients will learn it and will be able to access it.

To get early buy in and commitment, I think, on the part of providers to understanding that what they're writing for is for patients to have full access to all of their information is a critical piece upfront. And I'll just end with some of the things that we're really working on in terms of innovations – exam room design where we're building a new health center. We have three different groups of architects and designers working on an idealized sort of exam room design where patients have full access to the computers, even can actually sit in an exam room and input information into the computer themselves because I think that's where we're going to be headed. We want to be able to design the exam room for that now.

Language interpretation, to be able to use some of the new software that translates information from one language to another, to be able to get people to translate, to put information in a simple enough language that translation engines can begin to translate this information to people in other languages. Finally, people have talked about after visit summaries, which I think are critically important, but we're now designing a previsit summary where basically all of the patients, the things that people need to be concerned about, including what kinds of preventive measures they're due for in terms of their age and all of that would be presented to patients so that they can walk into the exam room and ask their providers for this rather than have the providers sort of be mandating this.

All of this is sort of part of overall transformation of the relationship. And I don't think it's about involving patients and families. It's around patients and families taking charge of their own healthcare, and it really is a complete and total transformation of the way we think about the provider relationship. And what we need to think about on the technology side is how do we build technology that supports that because that's where we're headed in the future. Thank you.

Christine Bechtel - National Partnership for Women & Families – VP

Thank you, Neil. Terrific. So we have Regina Holliday with us today and, Regina, thank you for joining us. I introduced you earlier, but in front of all these people, I want to say thank you because you have been a terrific patient advocate. Regina is a member of a coalition that we lead called the Consumer Partnership for eHealth, and Regina and other patients like Dave deBronkart, who I know we'll hear from later, have brought their voices to this debate in a way that few others can or, frankly, should have to. And I wanted to say thank you very, very much for the time that you devote to this, even though it is absolutely not your paid job, so we're very grateful to have you here today, and welcome. So we'll start with you, and Neil can hand you the mic.

Regina Holliday – Medical Advocate

Thank you so much. This is my husband's medical record. For two months, this binder went everywhere my husband, Fred, and I went. This information about Fred's kidney cancer was incredibly important. I fought for access for this information for weeks. The first hospital had a fully implemented EMR system throughout, and I was told by staff that we could not access the electronic record. I was told it would be a \$0.73 per page charge and a 21-day wait to get a paper copy. We were left without any thorough understanding of my husband's diagnosis or treatment plan, even though he was continuously hospitalized.

On Saturday, April 19th, Fred was told he was being sent home on a PCA pump. At that point, my husband told me to go after them and try to get him care. Fred was transferred to another hospital on April 22, 2009. He was sent with an out-of-date and incomplete transfer summary and MAR. Fred was denied care for six hours at the new facility, as the staff tried to cobble together a medical record using a phone and a fax machine. The next day, Fred's doctor sent me back to the original facility to get the entire medical record. The old hospital printed it out in 90 minutes.

I brought the record back and showed it to the new doctors. They looked at it briefly and handed it back to me saying, "It is safest with you. Fred might be treated at many facilities. But if you keep this with you, you will always have access to the record."

I read it in about three hours, and I was amazed at all the errors that it contained. I was amazed by the apparent lack of communication between staff members, and I found that many instances where if I could have just read the record, Fred's care would have been so much better. Fred lived for 56 days after we got a copy of the record, and there was not a day I did not reference it.

Why am I speaking to you today? This is why, because we are all patients in the end. We all deserve care and compassion. I was once asked to focus on what was the worst thing that happened through this entire tragedy. I told them the worst thing we experienced was a lack of access to my husband's data.

Why did I want complete and timely access to the medical record? I'm a regular person. I don't have a background in medicine. As many e-patient advocates state, I may not be an expert at my husband's disease, but I am an expert at my husband.

A caregiver is a vital part of the medical team. She or he has in-depth knowledge about the patient that can be utilized to provide the best care. We also must be viewed as two parts that make the whole, be it parent and child or husband and wife. This caregiving partnership is a vital part of the medical equation. Close partners act as information storage for each other. Often they diversify based on each other's strengths and weaknesses. My husband was a font of knowledge about ... and I handled the more mundane things like my son's IP process or a vaccination record.

Yet, my husband was told verbally, while alone, that he had tumors and growths. Not only was this information emotionally jarring and, therefore, very hard to process, it was ... spoken diagnosis to the partner with very limited medical understanding. HIT access to the test results would have been a far kinder fate. With access to the written record, my husband and I could have studied and researched the diagnosis in a timely fashion and made an informed decision.

Any system that denies information access to a caregiver or patient is not providing the best care. After spending hours reading my husband's medical record, I asked the nursing staff which employee reads the entire record of the patient, and they told me no one. They said the staff read the face sheet and the most recent pages, but no one reads the entire record. This is one of the ways e-patients can help the medical industry. We will read this data.

Once patients and caregivers have access, they can use that access to find out information about their disease. They can fully research their disorder and find out many methods of managing their medical condition. They can be part of the treatment team and using the Internet to find information that was once only available at remote medical libraries. And, using this information, they can make a truly informed decision.

Another amazing benefit of the EMR record is how we share that information. Due to easy access to an online patient community, we can have real time information on cutting edge treatments and communities like ACOR, patients who often sign off on a post with their names and abbreviated history of their disease. Patients and caregivers use Facebook, Twitter, blogs to address the particulars of their disease and to solicit help from an army of many. In this social media world, help is closer than the classic six degrees of separation.

A few hours after I tweeted requesting help from ePatient Dave, I was speaking to Dave's oncologist on the phone about my husband's kidney cancer. This kind of instantaneous access was unheard of in an age before social media.

In closing, I recently saw an ad from the American Hospital Association promoting adoption of the electronic health records using an incremental and a realistic policy. The images in the ad contained doctors and technology, but there was not a patient to be seen. When I'm speaking of HIT, I am speaking of lives, not livelihood. Patient access can save lives and it can stop soul crushing fear. I have spent the last year fighting for information access, and I say the time for incremental change has passed, and the time is now to demand rights to see our data. Thank you.

Christine Bechtel - National Partnership for Women & Families – VP

Thank you, Regina. It's a very tough act to follow, I will say. Very powerful story and, again, we really appreciate all of the time and energy that you devote to helping policymakers really understand what's at stake. Thank you. Dr. Gibbons?

Chris Gibbons – Johns Hopkins Urban Health Institute – Associate Professor

Thank you for the opportunity for me to share my knowledge, experience, and convictions regarding meaningful use of HIT in the real lives of patients and families here today. I'm extremely delighted to know that the meaningful use matrix recommended by the HIT Policy Committee includes the overall health outcome policy priorities of, one, reducing health disparities and, two, engaging patients and families in their health and healthcare.

The meaningful use standards have been carefully crafted to encourage progressive utilization of HIT by healthcare providers in order to improve efficiency, quality, and effectiveness of care. It is clear that it will take more than simply making patient records or healthcare processes electronic to improve healthcare quality and patient health outcomes. As our healthcare system continues to move towards shorter hospital lengths of stay and increase focus on self-management, aging in place, and patient centered processes, more "care" will inevitably be provided in the homes, in the home by patients themselves or informal caregivers who need decision support and technical assistance with the care processes and even the medical devices that they'll be using.

Yet, the meaningful use criteria seem predominantly focused on healthcare provider, traditional healthcare provider needs and goals with only an implicit or indirect, through the provider, focus on patients and caregivers. One exception to this observation is found in the stage 3 implementation beginning in 2015 when meaningful use will include patient access to self-management tools. However, no guidance is provided as to what these are or need to be.

In this country, we have about 700,000 physicians. We have about 1.5 million nurses. But we have about 356 million potential patients. Fixing HIT for all hospitals, doctors, and nurses is an important and needful task, but patients need support also.

Even as HIT without technical standards would yield little benefits for providers, the same is likely to be true for patients' electronic tools. The design of patient self-management tools without credible iterative involvement of actual patients will likely lead to lower than desired utilization rates or patient engagement. A reliance on such tools could actually increase healthcare disparities because of potential differential utilization patterns and, therefore, potential benefits across user population groups.

Seeking simple solutions for these challenges would not be wise. In my opinion, a staged implementation of meaningful patient use standards for patient self management and decision support tools included in qualified, complete, or certified EHRs or in standalone patient self-management modules should be developed and employed. Where the evidence does not exist, it should be evaluated and obtained prior to recommending specific standards. In the interim, ONC can engage relevant expertise to provide informed guidance. The available evidence regarding the following six questions can provide some preliminary guidance along these lines.

Number one, what are consumers' health information needs in the context of their real lives? Even as providers' needs differ, so too do patients' health information needs. However, patients often articulate a need to connect to emotional support and practical help for dealing with their health issues. Patient's self-management tools need to help patients and caregivers keep up with the latest information and health news. There is an increasing interest in wellness and healthy lifestyle activities in addition to disease oriented information and resources.

Number two, how do the results of ethnographic studies of individuals with chronic diseases affect our understanding of how HIT can improve their use of health information? Racial, ethnic, and cultural differences impact technology utilization in complex, nuance, and multifaceted ways. The underlying causes of these impacts cannot be fully explained by socioeconomic and geographic factors. Much more research is needed to provide a more complete understanding of the determinants of utilization, the implications of differential utilization patterns and, most importantly, how we can build upon this knowledge to insure equitable utilization and maximize beneficial health outcomes.

Three, what is the evidence base for patient benefit from their direct use of PHRs and other HIT that interact with EHRs? There is growing evidence that suggests patients can benefit from the use of electronic tools. Patients themselves report that when seeking for health information and resources on the Internet, they have generally been able to find what they are looking for and fully one-third of patients in one study indicate they have been positively helped by the information they found. In addition, a recent evidence report indicates that there is available literature suggesting that select consumer health informatics applications may effectively engage consumers, enhance traditional clinical interventions, and improve both intermediate and clinical health outcomes.

Four, what is the role of mobile applications? Many applications can be delivered across several types of platforms, including mobile technologies. Any value that a patient may derive should be attributed to the platform, the content, usability, and effectiveness of the application. In the same way that some drugs work better than others for different patients, we should not assume a one size fits all approach for the development, utilization, or implementation of patient tools and applications. Mobile applications then may have particular utility among some patient groups, while less utility among others.

Five, how can we use HIT to make information and knowledge actionable for patients? We must first understand patient articulated health information and health technology needs and desires. Giving patients data that is useful for providers will not provide value for most patients. Patients must see the information is relevant to them and helpful to them in order for them to use the information to make actionable decisions regarding their health and care. Asking patients what they want and need their

electronic tools to do will provide more help than developing tools based on only provider or expert insights.

Six, how does HIT enhance collaboration between providers and patients? Generally speaking, HIT can inform and empower patients, resulting in significant shifts in patient health practices and habits. Because health information is increasingly available to patients, it is in some cases disrupting historic doctor/patient/provider power differentials and impacting patient/provider communication in ways that can be uncomfortable for patients and for providers. Paradoxically, in some cases this can lead to poor quality interactions, which potentially affect care and outcomes, particularly among underserved populations.

Let me close with the words of Michael Angelo. "The greater danger for most of us lies not in setting our aim too high and falling short, but in setting our aim too low and achieving it." While the challenges of engaging all patients in meaningful use of HIT are real, the potential benefits of achieving this goal are even more substantial. Thank you.

Christine Bechtel - National Partnership for Women & Families – VP

Thank you, Dr. Gibbons. I'll be asking you guys exactly how to set the bar, so it's not too low, in the Q&A, so get ready. Scott, thank you.

Scott Mackie – IDEO – Client Relationship Lead

Thank you. My name is Scott Mackie, and I'm a member of IDEO's health practice, and I'm based in Boston. IDEO is an international design firm that helps organizations to innovate, and I'm here to represent them, but I do not claim the deep IT or medical experience that some of the others here today have. It's more that we've been invited and we're deeply honored to be invited to share our general expertise in human centered design.

We're starting to sound like a chorus, I think, so I'm going to make two simple statements. The first is that with all due respect to the people who are devoting their time here today, we feel that the issue of usability is not receiving sufficient attention from the Health IT Policy community. And the second is that the only way to achieve usable systems is by deep involvement of users, real people at every stage of the technology development process.

To my first point, usability is, by definition, critical to the success of health IT systems. All health information is entered, received, and acted upon by people. There is no point to information technology unless it is used and used correctly with positive impact. And, unfortunately, usability also presents the greatest risk of introducing additional errors and unwanted effects. To the unwanted effects and unwanted behaviors, and to the health system, as Chris said, machines will very rarely make mistakes if they're designed well, which they will be. But people will make mistakes if the machines are difficult to use.

As I say, our first message is that it needs more attention from the policy group, not just from the business community. And just because usability problems are perhaps in some ways less tractable than percentage uptake or privacy legislation or database interoperability standards, that does not mean that it should be left unfettered. To the contrary, it should be regulated and strongly supported by the government in the most careful, most astute, and most human manner possible.

And the second message is that policy needs to strongly encourage and, where feasible, mandate appropriate involvement of the end user throughout the design and development process. This means that during the design process, we should be working alongside doctors to figure out how they can

actually make use of five days of ECG data, which is otherwise just overwhelming. Sitting with patients as they try to understand what their stat CBC test means, and talking to a mother who has to manage her child's diabetes medications, her husband's heart pills, and her father's rest home care 100 miles away.

We can use this information to design solutions that fit into people's lives, that help them to make better decisions and that actually change the status quo. I was incredibly pleased to read that Intel is doing exactly this as they design new tools.

Conversely, I was also driven to greater resolve by the recounted experience of Regina who, together with her late husband, had to fight to access his health information only to find that it was full of errors and that nobody had read more than a slice of it. Regina's experience demonstrates the very human failings of healthcare professionals and, yes, patients have those failings too.

In our work at IDEO, we meet many people with less serious or apparent conditions who failed to use health IT tools due to intimidating, unusable, or simply uninteresting design. We see many more examples, however, of the capability and bottomless motivation that people and their caregivers have to understand their health information and to act upon it correctly to everyone's benefit. Too often systems and policies are developed in a laboratory or a meeting room or a conference room where the developers imagine people as always rational, entirely focused, yet universally lazy, either perfectly professional or hopelessly uneducated.

These caricatures are not a good basis for design. Real people forget. They get bored. They get busy. But they usually care a great deal. So solutions need to be developed in a way that recognizes these human factors. Real end users should be engaged throughout the entire invention, iterative, development and testing stages of health IT systems. Together, we should strive for policies that incentivizes this kind of design for use.

In summary, again, please give this issue more attention and please insure that users are involved in the development of these systems. Thank you.

Christine Bechtel - National Partnership for Women & Families – VP

Thank you, Scott. Terrific work. Eric Dishman?

Eric Dishman – Intel Digital Health Group – Director Health Innovation & Policy

Well, I am also honored to be here today. I'm part of the chorus, and I think we're singing pretty well in harmony so far, and I think I'll continue that. It's really important to me that we're talking about using health IT to facilitate family and patient engagement, and this is really about health, wellness, and care, not just about medicine.

I've been doing social science work in this area of patient engagement for 20 years now, and the last 11 of those at Intel where we've actually lived with and observed 1,000 elderly patients in 20 different countries. I mean, we go in the mornings, the evenings, the nights, the weekends, the holidays, and try to understand cross cultural commonalities and differences amongst those. We've done more than a dozen pilots of in home technologies, particularly for seniors and chronic patients. We've got two, 300 household cohorts of seniors: 300 in Oregon where I live, and 300 in Ireland who come in to Intel facilities and teach us and help us co-invent and design these technologies. And we have funded almost 100 university grants in this area of chronic disease and independent living technologies, so we have a lot of practical experience of installing IT systems in people's homes.

These are IT systems that allow clinicians to know the actual vital signs and trends of a CHF or a COPD patient and to intervene through a virtual video visit well before it becomes an emergency room visit. These are IT systems that have helped seniors with cognitive decline to actually continue cooking or calling friends on the phone with the help of a wireless Internet work in their home, while feeding behavioral markers about the changes in those daily activities back to their neurologists and their neighbors who are part of the care team.

These IT systems have enabled nurses to customize care plans and medication routines with just in time reminders and coaching to their diabetes patients via a watch, a television set, a PC, a phone, or whatever device the consumer was comfortable with. And these IT systems have helped pick up the early signs of the onset of dementia or the increasing risk that a senior may fall well before those become crisis moments, and often before even the clinicians and the families were aware that there was a problem.

Professionally, my career is great. Things couldn't be better. We're making small, but important, meaningful use of health IT with these patients and families and providers for about 1,000 households. And these things help with prevention. They help with early detection. They help with self-care, and they help with behavior change.

Personally, things aren't so great. I'm a patient with multiple chronic diseases myself. I can't get access to my own data, electronic or otherwise, or I can't find one doctor to jockey what's going on across all of my conditions. As a grandson who cared for a grandmother with Alzheimer's many years ago, I still can't go buy technologies that I know could help someone like her because there's no real marketplace yet. As a son trying to figure out how to care for my aging parents across the country in North Carolina, I live in Oregon, I can't even help them with the great prototypes and products that Intel has built because there's no infrastructure and incentives for their own physicians who actually adopt and integrate these things into their workflow. And, as a citizen, I have to be honest. I can't have hope in a clinical-centric healthcare reform effort that so far has failed to create a national plan for shifting care from scarce, over-utilized hospitals and clinics to abundant, underutilized homes and consumers in the midst of this global aging crisis that we face.

In my oh-so longwinded written testimony for today, I laid out more than a dozen recommendations and in the blog for this hearing, I narrowed it to five. Because of time, I'll narrow it to three right now. First, I think we need to create what I call a Y2K+20 commission of top government, not-for-profit and industry leaders whose mission is to help our nation prepare for the global age wave by investing in infrastructure that moves 50% of care done in institutions done today to the home by 2020.

Second, I think we need to use the stimulus and discretionary funds in the national institutes to build a national cohort of 10,000 elderly and other patient households with next generation broadband to test out these promising personal health technologies and care models and accelerate their commercialization and best practices beyond the small pilots that exist today. Then, third, in the healthcare reform bills where CMS and others are going to be doing experiments around accountable care organizations and medical homes, let's make sure that educated, engaged patients and family members and the IT to support them that goes all the way to the home and the community are a part of the meaningful use in those care coordination teams.

In conclusion for me, the meaningful use of health IT is a lot more than just having access to an electronic version of your chart. This is technology that's going to allow us to do care differently with different resources and in different places. Sometimes those places are going to be at home, at work, and on the go, in addition to traditional clinics and hospitals.

I argue, based on the research that we've done, that it is unethical for us not to use health IT that's largely already here to move care to the home and to the community and to the consumer for a lot of healthcare needs because, in many cases, personal healthcare at home will be better, safer, and cheaper than clinical encounters. In many cases, there's no face-to-face equivalent because these technologies are generating new data types, new insights about trends, and new communication channels for personalizing care that just can't be done in a quick exam room visit.

So, thus having seen the promise of personal health technologies professionally for the last two decades and very, very much needing them personally in my own family for the next decades to come, I really encourage us not to stop after a day of hearings on this important topic. We need to weave these ideas and inventions into the fabric of our 21st healthcare system for everybody. Thank you.

Christine Bechtel - National Partnership for Women & Families – VP

Amen and hallelujah. Thank you. This is a terrific panel. We're going to open it up for questions, but first I want to say thank you very much to our panelists and also to Josh Seidman who played a huge role in helping us shape all these panels today and is part of the reason why we have the chorus that is really singing well together and, of course, my fellow workgroup members. So we'll open it up for questions from the workgroup. You know you want to, Paul. I can see it.

Paul Tang - Palo Alto Medical Foundation - Internist, VP & CMIO

I want to open up by saying this panel has more than lived up to the already outstanding expectations that they deliver the meaning of what we really want to achieve. The meaningful use workgroup, I'd have to say, is part of your chorus because I think one of our proudest moments is introducing the category of engaging patients and their caregivers as a meaningful use of "EHRs", as you see that we've really pushed it out to not only PHRs, but how do we engage people using this tool.

I think all of you touched on more than just the transformation of HIT. You're asking for the transformation of care in health, and the delivery system, I think, the statistic that Chris was talking about. You have a few million healthcare professions. You have 350 million people. In the IOM study looking at the workforce for aging America, we talked about, I mean, there was one estimate that there's \$350 billion of goods being delivered through service of caregivers. We just haven't provided them with anything: data, knowledge, tools, and I think that's the transformation you're asking us for.

In a sense, I think we, as healthcare professionals, have to ask ourselves how do we earn a spot on the patient's health team rather than what is it that we can do for these people that we treat. It's really the opposite. So you've given a number of recommendations. This is going to be a hard question, but what policies could help move the country to shift the way that Eric talked about, shift the entire focus of attention, the marketplace.

What policy or policies would start that shift going? And in a sense, it is not even asking only for an HIT policy because what you've been talking about is a change in our whole "healthcare delivery system," and it almost seems like we need a policy that makes a mind shift of the entire country, and surely the HIT will have to be there to support that mind shift. And I'm not sure how clear I'm being, but it's really what's the policy. Eric presented a number of things, the Y2K+20 commission, etc., to go ... but what kinds of policies do you think would help the country's mind share to shift?

Chris Gibbons – Johns Hopkins Urban Health Institute – Associate Professor

I can give you my thoughts, Paul. It's a good question, and it needs an answer. Before I answer that, I would say I think the shift actually is already happening, so it's not something we need a policy to push,

although policies can help the coming transformation, whatever it would be. If you look at what patients are doing, in our book on e-health solutions for healthcare disparities, we use the example or we looked at the example of online utilization of the Internet for health resources as a proxy because a lot of these things haven't been developed.

And every time I look at the number, it continues to go up. The last time I looked, it was over 160 million people searching the Internet for health resources and health information, 84% of the adult user population of the Internet. And they're not just looking for medicines in the high quality hospitals. They're looking of lifestyle and all these other kinds of things, but now data is even coming out saying that one-third of them say they've been positively helped.

What does that mean? We don't actually know, but the point is they believe they're getting something there that they're not getting from the healthcare system, and that's why they're going there. For me, that's only going to continue. They're drawn to the anonymity, the convenience, two things we don't have in our healthcare system, right? It's a 9:00 to 5:00 profession, except for the emergency room. So I think it's happening, but I'll let others comment on sort of broader policies, which also need to be there to continue the emergence.

Paul Tang - Palo Alto Medical Foundation - Internist, VP & CMIO

There might either have to be a policy in place or policies that are blown up, so let me just open that too.

Eric Dishman – Intel Digital Health Group – Director Health Innovation & Policy

I mean, I'm with Chris in terms of, in some ways we need to get policies that get out of the way of baby boomers and let them transform healthcare like they have child care and every other institution in our society. I mean, the challenges that we have of getting the kinds of systems that we've tested out on a small scale to a large scale are so numerous that the first policy that we need is we need a place. This is why I'm pushing this idea of a commission or something, even though Congress hates commissions.

We need a place to stand where we can work on all of the issues because they get relegated to somebody that focuses on technology or somebody that focuses on workforce. And the problem is this is why you end up doing comprehensive healthcare reform. There's no place from which to stand in which you can innovate the financial incentives and the workflow and the workforce training and the IT. That's why I push for this idea of a commission.

When I come to Washington and have for ten years pushing for these kinds of things, we get what I call the Washington runaround. We literally get agency after agency saying, "Wow, those are really compelling technologies," or they may be skeptical and say, "Where's the evidence?" Here's what happens. They'll point and say, "Wow. That's really compelling. But go to those folks and go to that agency."

So it's the runaround town, agency after agency, department after department saying not my category, not my purview. And then right when we're walking out the door, many times the heads of those agencies will say, "By the way, can I have access to that technology for my mom. She would be a really great candidate for your pilot."

So, as part of it that we need an interoperable government. Everyone talks about interoperable technology, right? We need a place from which we can stand to get all these agencies to work together in a concerted way, and that's hard, hard human behavior to change.

Neil Calman - Institute for Family Health - President & Cofounder

Paul, just to try to focus in on your question, I think one of the most profound things that we could do would be to really push this piece that we've been working on, which is to give people complete and total and instant access to their information wherever and whenever they want it in the healthcare system. I think we're moving in that direction, but I think we've been halting it at times about that. And that includes on the inpatient side, the outpatient side, the home health side, everywhere.

People need to have instant access, and they need it in an organized and intelligible way. I think that if we really push that, it's more than just the information, and it doesn't deal with all the transformation to the home stuff. But what it does is it fundamentally changes the power relationship in the provider patient relationship. I think that until we make that fundamental change, we're going to keep on knocking at the door of this issue.

I will tell you that I was in a hospital with my father-in-law for the last couple of weeks, and in an intensive care unit as a physician in a hospital that's a few blocks from the hospital where I have privileges, and I could not get access to his information. I could introduce myself as a physician. I could talk to the staff. I was not allowed to look at his medical record. I was told by both the nurses and the administrators that I did not have privileges at the institution. I could not look at his medical record. I couldn't look at the EMS record when he was brought in. We knew nothing about how he had gotten to the hospital or what had happened to him. I mean, this is just the intensity with which the system protects information as if it owns the patient's information is something that we could deal with in a very, very concrete way, and I think it would fundamentally change a lot about the healthcare system.

Regina Holliday – Medical Advocate

And I would like to add, one of the major important things we could work on is visualization of data. We live in a visual society, but we have text driven medicine, and that is part of the disconnect we have with the broad public. One of the reasons the first murals I did was the medical fax mural based on nutrition fax label because anybody can understand that. It's simple. It's clear. It's precise, and it's visual, and that's one of the ways we can change things.

Scott Mackie – IDEO – Client Relationship Lead

Can I make a final comment? I agree with the other panelist's comments around information and particularly in that it creates pull rather than sort of expecting that policy will push change. By allowing people access to information, you'll automatically generate demand for the services to process that information. And that means that you'll open up the power of the business community, just like Intel, to actually affect these changes and people like Google Health, etc., who can provide the visualization techniques.

However, I think there's another barrier behind that, which is around liability. So we've worked with companies who wanted to do great things around health IT and social media, but they are unable to do that because when they get involved, they immediately then become liable for the information that is provided there. So I think there's perhaps another issue around liability at the back end of that.

Chris Gibbons – Johns Hopkins Urban Health Institute – Associate Professor

Paul, just one more thought. I think, two things that you've already done will help this ... you said in the beginning, putting engagement in as part of the definition of meaningful use will begin to push this because now you have to look at it, and especially in stage three where the language says patient oriented tools. Now you can just provide a tool, and we know that's not going to do anything. So coming up with standards and everything else that we're doing here to try to get at some of these tough issues will be those policies that will help us go in that direction.

Paul Tang - Palo Alto Medical Foundation - Internist, VP & CMIO

I have a follow up. As Regina said, the time for incrementalism is over in a sense that we have more than the 2017 bankruptcy of the Medicare trust fund is one of those events that's going to happen. What Chris said is there's already pull. There's already a change happening. I'm of the mind that there are many policies that are getting in the way of that pull.

Now at least most of you talked about access to the information, but I'm struck by what Chris said, which is access to the information that providers wrote for themselves. Is that good enough, the question is. I'm not sure I was clear by looking at some of the Chris said that you want access to information that providers wrote for other providers. Is that truly what you want? Is that what you—?

Chris Gibbons – Johns Hopkins Urban Health Institute – Associate Professor

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Paul Tang - Palo Alto Medical Foundation - Internist, VP & CMIO

It seems like that is insufficient, that it's not good enough to give patients access to what we wrote amongst our little secret community. We need to do something far above and beyond that, which is give patients and their loved ones access to the information they can use to help themselves to mobilize the 350 million. Comments about that or what's in the way of that happening?

Eric Dishman – Intel Digital Health Group – Director Health Innovation & Policy

This is probably an unpopular thing to say, but I'll say it. I've been doing patient advocacy for cancer patients for 20 years, and I will tell you, HIPAA, as practiced, and that's not what's actually in the law, but it's the perceptions of HIPAA by provider communities is actually hurting patients in many cases. In my own experience with trying to get my own data directly, as well as with other patients, we'll get a nurse or an office worker who says I'm not allowed to fax that to you. I'm not allowed to e-mail you because of HIPAA. Right? And it's like well show me where in HIPAA it says actually you can't do these things? There are some things that you need to do. So it's the sort of reaction to HIPAA as opposed to maybe what's actually in the law that has really got a lot of misperceptions out there that actually make it more difficult.

I know patients who are trying to get all of their data together to get onto a clinical trial, and they can't get on the clinical trial in time because they're dealing with so many different hospitals who have such HIPAA phobia, right, that they just can't make the information flow. That's one that I think that we actually need to look at.

I actually don't know what the installed regular use of PHRs today. I still think there's an imagination problem. I think if you took Dossia and Google Health and Microsoft HealthVault and combined all those folks, I suspect the number of people who are actually using a PHR in any sustainable way beyond sort of initial login is very, very small, and I think it's an imagination problem. People don't quite imagine how to have interactions with the – the clinical community doesn't quite know how to conceive of how to do communication using these things.

It's like when we just started putting EHRs in the exam rooms and laptops. We had to learn how to use those communications. I just don't think we have an imagination for it in the consumer side or on the clinician side. So we need to do a campaign that's about PHRs and educating them and what they do and how you would sort of integrate them into your life because I think that the install base today is incredibly small.

Christine Bechtel - National Partnership for Women & Families – VP

I know David has a question, but I want to follow up on that point directly. One of the things I think we've struggled with is this notion that if you unlock the data, that's clearly a barrier, right? So PHR use, California Healthcare Foundation just did a study. I'm looking at ... I think it was 5% to 7%; 7% of patients are now using a PHR, which is up from 2%, 3% a couple of years ago, so that's the good news.

But the bad news is I think that the part of the reason it's a challenge for patients who use a PHR is because you're often entering your EOB into the record. I know I signed up for HealthVault one time, and haven't looked at it in, like, I don't know, four years or whatever it was, right, like the rest of us. So part of it is that it's cumbersome to get the data, get it in.

So if I think about the context of meaningful use, and I think that we've begun to unlock some of that data, we hope, by giving, through meaningful use, giving patients access to their own health information within 96 hours doesn't require though that it's portable. We're not giving folks, at least in the proposed rule, resource materials to actually understand the information that's been presented and use it in a way that is meaningful to them. And I think that points to some issues around both the liquidity of data, but also the tools themselves, and so I'm kind of curious to the whole panel's reaction.

Scott, you talked about user-centered design. Tools that allow patients to use information for multiple purposes to me are more valuable than just sort of moving the information, although that clearly has some value as well. My question, following up on what Eric is saying is, all right. So what happens if we solve our imagination problem, and we figure out some very cool things? What can we do in the meaningful use criteria in the coming years to really drive and support innovation in this space, to really spark the imagination?

I heard a lot of themes. I heard patients want information for decision support. I heard access for sort of error correction purposes, design features that really matter to patients. How do we incentivize that? What do we build into the criteria for meaningful use next payment year to move us in that direction?

Eric Dishman – Intel Digital Health Group – Director Health Innovation & Policy

For me, I think we're kind of starting with the boring part, which is the gathering of the information.

Christine Bechtel - National Partnership for Women & Families – VP

Right.

Eric Dishman – Intel Digital Health Group – Director Health Innovation & Policy

And we need to start with the conversations, so in almost all the systems that we build, we create a space, an online community that allows families and patients and providers to communicate in lots of diverse ways. Once you create that forum for interaction, they start getting the information in, right? It's almost like we're trying to build databases and records and things that are kind of boring and do have a lot of heavy lift to them. Well, what motivates you to go through all that pain? It's interactions and conversations with other people.

We use, for example, Microsoft now owns it, Groove, and Microsoft is a computer supported collaborative work tool. One of the first things that Groove allows you to do is to do shared sticky notes with other people that you've invited into your space in a shared calendar. Once you do that with patients, clinicians, and others, then everybody else starts putting the information in. But a lot of the folks within PHR start with the data and the information, which is like the most boring and painful part. Start with the part that has immediate value, interacting with others, and then they'll pull the information along.

Scott Mackie – IDEO – Client Relationship Lead

I'm not sure how this translates to a policy tool and how you create a criteria that leads to this as such, but I think that, going back to your point, Eric, about imagination, we go out and we talk to people all the time. And we can get fairly – it is hard for people to imagine. And the way that we help people to get around that is we take them some design. We take them some prototypes, and I think you've seen it in many industries with demonstration initiatives, so sort of these test beds. I think they are a policy tool that's used at times where there's an investment in creating something that shows you what these things could be capable of, and that then creates the ... people to want them and to invest in them and to see just how great they really could be. I'm not sure how you would drive that through a criteria as such, but I believe that prototyping and bringing these things to life in a way that people can get excited and have a conversation about it and get imaginative themselves then and build on those ideas, I think, is one of the first steps.

Eric Dishman – Intel Digital Health Group – Director Health Innovation & Policy

A meaningful use vision video would go a long way, in all seriousness, right, a well-produced, meaningful use vision video that shows how all the constituents work together.

Chris Gibbons – Johns Hopkins Urban Health Institute – Associate Professor

There is a guy, and I must be honest, I'm blanking on his name. He's in Europe somewhere, an IT guy that says the degree to which technology will be useful, valuable, and effective in people's lives, and he wasn't just talking about healthcare, actually. It will be to the degree to which it becomes invisible in their lives.

So the idea of building something over here to do something is one way of doing it, but thinking how we can build tools to add value to people that fit into their lifestyles or with the tools, broaden the tools that they already have is a better way to do it. And so why does the health encounter have to be in this sterile, cold, boring place that no one likes to go to and happen in ways that are unfriendly? Thinking about that, and again, starting with a problem rather than a tool or the data, and then incentivizing that invisibility or that seamless integration with lifestyles, it may lead us to places we're not even dreaming of now, but I think that's one way.

Neil Calman - Institute for Family Health - President & Cofounder

I'm going to go back and try to bring us back to the policy thing and basically make another recommendation for a very concrete place that we could go, and that would be to mandate that systems have to have the capability for electronic visits, for e-visits because all of the stuff that we're talking about, transforming the locus of care, in spite of the fact that I know that there's a lot of stuff that goes on, patient-to-patient, and I use that stuff myself.

When I get sick, believe it or not, the first thing I do is go to the Internet if there's something weird going on and look for information. I've done that twice in the last two weeks, and I'm not a hypochondriac. But I found out stuff that my doctor never told me, and it actually cured my illness, so I'm a big advocate. But I also think that by restricting the communication between providers and patients to either a five-second phone call, which is always frustrating, or a visit, which is so inefficient, both on the provider side and the patient side. We can completely transform that. Electronic visits should be mandated. All systems, I think we should require that systems at some point in the future be able to do that.

And I think we need to send a policy message about payment for those kinds of visits so that we can begin to open up different paths for communication. We've been doing that through a patient portal, and I can tell you that the most intelligent and thoughtful conversations that I've been able to have with my patients have often been around e-visits because they take the time to construct what it is that they really are concerned about, and not in the pressure of feeling like I'm going to get up and leave the room in two

seconds. And I can take the time actually to research and be more thoughtful about and more timely with answers that I give them. And I think that that's one very concrete thing that we could call out as a requirement.

Eric Dishman – Intel Digital Health Group – Director Health Innovation & Policy

Here, here. I completely agree and don't prescribe it to be a particular medium. It baffles me that we'll give clinicians the power to make life and death decisions over surgical procedures and drugs, but we won't give them the flexibility to choose what mode that they need to interact with the patient. Is it secure text messaging? Is it a video visit? Is it an in-home visit? At the end of the day, we're talking about care flexibility as a fundamental principle that we need to be able to make professionals empowered to make choices about how they interact with their patients and then give them the infrastructure to do that.

You're going to stumble upon the third rail of health policy, which is going to be licensure, and it was something that didn't get talked a lot about in the health reform debate, and we're going to have to do it. If we want to achieve the economies of scale that are needed to integrate these technologies and to have virtual call centers that can reach out to regions, we're going to have to deal with the state licensure versus national licensure issues, at least for new kinds of telehealth workers and other kinds of folks who will be trained in informatics workflows to use these technologies.

Christine Bechtel - National Partnership for Women & Families – VP

David Lansky.

David Lansky – Pacific Business Group on Health – President & CEO

First of all, let me thank you all for your testimony and for your testimony and for the lives and careers you've put into this work. It's incredibly valuable and heartening to hear what you've all been doing and bringing us to this point, this milestone, I hope, in moving this forward. I think we all share the chorus you sang about where we want to get.

We have a few tools at our disposal in this process that was created by the stimulus bill, and the work of ONC subsequent to that. And I think we understand that there are a lot of tools that should be brought to bear to make this transformation happen, but we only get to flex a couple of them. And so, as you've heard already from a couple of us, the meaningful use program is one of those tools. And I'm wondering; I want to pose one potential way to approach the meaningful use criteria for 2013, 2015, and see how you react to accomplish this shift, as Eric described it, towards home-based service models, and less of an office-centric model that Chris just described.

So I categorize, we have positive incentives we can manipulate, which are the ARRA incentive dollars. Then there are all the negative incentives, a perpetual fee for service payment that just keep pushing the vast majority of healthcare funding into the traditional system. And so the question is how do we motivate people to begin to shift the way they use the dollars they have to direct care in other media formats, settings than the traditional ones.

I'm wondering if you think if we were to emphasize use of incentive dollars through meaningful use for outcomes, for health outcomes of several kinds, would it do the trick. For example, we've already got blood pressure control as a measure of outcome that is implied in the meaningful use matrix. If significant incentive dollars were attached to chronic disease outcomes of that kind, and the providers and patients were given open ended mechanisms for achieving that goal, regardless of whether it involves office care or not, would that help stimulate the marketplace Eric mentioned to deliver in-home methods for improving blood pressure control?

Similarly, if we were to measure something like SF36 emotional scales to get at the emotional dimension that several of you highlighted of quality of the patient and family experience, would that help to shift some of the service delivery toward social support and emotional support for the family and patient? Similarly, if we had a patient experience measure that measured whether or not – several of you in the written testimony today commented on the importance of measuring whether patients are feeling the value of EHR adoption in their own experience of healthcare.

In those three areas, let's say, chronic disease outcomes, emotional health status on an emotional scale, and patient experience outcomes, if we were to heavily weight incentive dollars for achieving those kinds of metrics, would that stimulate the shift that you are all recommending or not? And if not, how would you adjust that approach?

Eric Dishman – Intel Digital Health Group – Director Health Innovation & Policy

I particularly like the one; we call it sort of social health. I think all of those things would help if you create conditions upon which you're testing the end-to-end experience. What I mean by that is what we observed today is a lot of health plans, hospitals, or whatever will go try a telehealth pilot or an independent living technology pilot. And they ask the clinical teams to, in their spare time, take on an additional panel of patients and manage them holistically. Here are your incentives to do it. But it's done literally after 5:00, and they don't actually change their workflow or remove any of their old job while testing out the sort of new job. And it's not surprising then that these pilots come back and they're not sustainable, or they're done when the grant is done because they're exhausted, and no one sort of optimized the workflow and let them really do the experiment properly.

I think the focus on measuring social engagement is really good. Across every study we've done in all 20 countries, cross culturally the most important variable for us about the overall health and wellness of the family is what we call size and permeability of the social network. Permeability means sort of think about it as the families, regardless of financial, I mean money does matter, but it doesn't matter as much as sort of size and permeability of social network. If they have an impermeable social network, meaning they don't let their neighbors come in and visit and sort of see how they are, and they sort of pull up the drawbridge, then they struggle with all kinds of other health outcomes after that.

If they are very porous in their permeability, and they have a very large social network, in some sense so goes the social network, so goes their health. And I don't think we pay enough attention to that. So I think, if you could build incentives and ways of measuring that in a meaningful way, I think it would drive some really good behaviors.

Scott Mackie – IDEO – Client Relationship Lead

I think Eric skipped sort of the background to his very, very insightful point around testing, which is that we don't know the answer to your question. You have to test it. And apparently, from Eric's testimony, you have ... in a realistic manner, and I think that would also go along with how IDEO would approach this problem is get a test out there and learn from that test and figure out what might be the negative effects of doing that and figure out how effective it might be in actually changing behavior. But the point is to test it, and test it before you release the criteria also.

Chris Gibbons – Johns Hopkins Urban Health Institute – Associate Professor

Yes. I think those would be helpful. I think it's beginning to get to what, I guess, pretty much other sectors have a more customer, consumer orientation when satisfaction of the consumer is valued much more so overall as an industry imperative than it is in healthcare, and those kinds of things make that more important. So what I'm thinking is incentivizing those conditions or those things would create conditions that would be helpful. And if you could also work around opportunities and new collaborations,

and what I mean is the home is one setting. There are other settings that are equally important where innovation could occur and might be achievable faster. The worksite is another, especially for large self-employers.

I was at a conference ten years ago, and they were saying healthcare dollars are our single largest bottom line factor, and we're not going to sit here and let it just bowl us over. We're going to define healthcare of the future. So I thought it was a little interesting, but they were the chief medical officers of the nation's largest companies, so they have desire, money, and incentive to innovate around achieving better health ..., so creating some policies that look at those kinds of things, as well as new opportunities in the home and in the workplace.

Then, finally, new collaborations on the clinical side, meaning not just multidisciplinary teams of physicians and allied health workers, but also collaborations where the physician or the healthcare personnel are managing it, but with gymnasiums and grocery stores and others to see, can we incentivize, through our healthcare system, more collaborative approaches for things that we know patients need to do or we all need to do to achieve better outcomes, rather than just saying healthcare is something that happens in this place and that place. And when you go over here, you're not thinking about it anymore. I think, if there was a way to do that, and I think there are through policies, at least in an experimental and demonstration way in the beginning and then learning on those principles can really put them in here.

Regina Holliday – Medical Advocate

It's really important to remember the hospitalized patient and caregivers and waiting, people who are waiting in the hospital. One of the number one people complaints, reasons people complain about not uploading information is they have no time. Yet, we have patients who have nothing but time on their hands and have no access to a portal, have no access to putting more information in. We need to reevaluate how that is done and make that one of our first steps to making sure because there is no person who is more interested in their health outcome than the currently hospitalized patient.

Christine Bechtel - National Partnership for Women & Families – VP

George.

George Hripcsak - Dept. of Biomedical Informatics Columbia University – Chair

Again, thank you to the panel, and I agree 100%, and I'd like to take the opportunity to ask for help. This panel in general is set up to say what can meaningful use do to help patients and families, and I want to ask what patients and families can do to help meaningful use. It's kind of funny. You go around the country, and people feel like you're deciding how electronic health records are going to look three years from now. Actually, what you're deciding is what criteria to suggest to a government agency, and even that agency gets to then set criteria for a small to moderate sized incentive, and perhaps some distant penalties.

But really, and then everyone thinks someone else is going to get meaningful use done, and they just need to be able to make sure it benefits them sufficiently. So we have to take Chris' numbers. We have 300 million people total thinking it's someone else's job to do this, and we have 12 people on a panel trying to define this thing, so we need better odds.

In the theme of ask not what meaningful use can do for you, but what –, I mean, how can we bring in patients to push this whole thing forward? It may be through things like defining meaningful use criteria that excite people, which is, I think, what we've come up with. The video was a good idea and so on. But

kind of like more thoughts on the idea of how we get society, people, patients pushing this thing to succeed, so it's not us going on our own, from all of you, Regina and others?

Regina Holliday – Medical Advocate

Of course, I'm a major proponent to painting and visualization, and that's one of the ways we can get where we need to be. One of the major problems is people don't understand what meaningful use is, and we have to explain it in a way that they do. And I think the video idea is actually excellent because that's one of those beautiful ways that you can show people very quickly. You need to show people very quickly how this affects them, and that would be a beautiful way of doing it.

The other thing is to remember that things that are just accepted in our regular lives aren't even present in medicine. Until you fall into the world of medicine, you don't realize there's this massive disconnect. Like I didn't realize that there wasn't an information act, a Freedom of Information Act to medicine. I was floored.

I was like, "What? You mean you just can't get this information?" It astounded me. And when I speak to people on the street, because I publicly paint, I speak to people every day, and they have absolutely no idea they can't instantaneously get their medical information until you tell them, and that's what we need to do. We need to have a public campaign to make it very clear of how challenging it is to get this information without meaningful use and how much this is going to affect our future lives.

Eric Dishman – Intel Digital Health Group – Director Health Innovation & Policy

You can ... practical. You can require every REC to have an ethnographic design team built into it or access to a consulting agency that can do that – plugging IDEO here – and, quite frankly, do what we do. There's a group of Alzheimer's and chronic disease patients who come into Intel once a month and kick on our ideas and say, "That's horrible. I don't understand it. It doesn't translate right." If you imbed both ethnographic and participatory design teams into all these regional centers where we're doing education about health IT, then things will change. You just literally have to open the door to them.

Chris Gibbons – Johns Hopkins Urban Health Institute – Associate Professor

I think a couple of things. In the certification of health IT tools, you could think about, in the standards that you use or whatever the criteria are to determine a certified tool, the developers would have to show paid credible creation, involvement, either through user centered design, which I think is critical, also attention to human factors, issues beyond just the sort of assumed, broad level ones. That documentation would have to be provided to say that in the design of this tool. It's not just technical standards that allow information to transfer, but we tested, we looked at, and we evaluated these aspects of patients and modified our systems in this way.

And I would say it's an iterative process. I don't know the periodicity, but it's not just do it once and it's done forever. So on the certification side, you could do some things there, I think. Those are some thoughts that come to my head.

Scott Mackie – IDEO – Client Relationship Lead

And I think, often people, when we talk about adding these test processes, etc., people get concerned that this will add additional cost and burden upon people, and that it might actually discourage innovation. I think it doesn't have to be as involved in some ways as you'd think. That's the point of the iterative process is that the early tests can be very simple. And, in fact, I would challenge people to develop health IT systems in a way in which, in the first few months—you know, this is just a provocation—that you're specifically excluded from using any kind of technology, but you have to focus on what it is you're

actually doing for people and what's the problem that you're solving. And then you apply the technology to solve the problem rather than having a technology and saying, well, what can we do with this then.

Eric Dishman – Intel Digital Health Group – Director Health Innovation & Policy

Start with cardboard boxes and clay. Crayons, cardboard boxes, and clay, that's literally what we start with in the design process for these health IT systems with consumers.

Neil Calman - Institute for Family Health - President & Cofounder

One of the things that concern me is a little bit about the political process by which the meaningful use criteria get vetted. So I think that our workgroup, in a sense, has been very pro patient pro family, pro consumer. But from what we hear about the responses from the industry, the people who know and are tracking meaningful use are industry representatives, people from hospitals and medical associations and supply companies and EHR companies, and people who, not all of them, but many of them have a huge investment in maintaining the status quo.

And I think, until we get out there and sell meaningful use to the public, what happens is every time we come out with something, the vast majority of the weight of information we get in response is going to represent the people who are interested in maintaining the status quo. And we know that that drives the political process. We know that that's going to slow down innovation. And I think that we need to figure out a way to get to the consumer so that we get the weight of the responses of consumers that say, "You're damn right. We need instant access now. I don't want any more excuses for why people can't do this. We want this stuff We want it this year. We don't want it in 2013 and –," but we're not going to see those kinds of responses. We're going to see the predominant responses from industry.

Who makes the newspapers? Who makes all the It's all of the industry representatives that are talking about how things can't happen on the timeline that we're needing it. I love the way you say it's the incrementalism, but that's the response you get from industry, more incrementalism. Slow it down. Take longer to achieve the things that we're trying to get. So we need to get those voices in the political process so that every time there's one of those responses, there's 20 consumer organizations or people basically saying no. Every year that we wait for this stuff, more people are dying unnecessarily, going without their information, suffering adverse outcomes.

Christine Bechtel - National Partnership for Women & Families – VP

That's a perfect point for me to jump in and say—thank you, Neil—that I agree. We need to do a better job engaging the public, and I'm hopeful that ONC's public engagement plan will reflect those needs. We, yesterday, sent an e-mail alert to 45,000 people about meaningful use and asked them to weigh in with the Secretary, and asked them to say, "Stand strong, do things that are meaningful for patients and that give taxpayers a return on their investment." So the numbers are still coming in, but as of last night, I know that more than 4,000 people had e-mailed the Secretary, so it's very exciting, so more on that hopefully in the press later today. Other questions from the workgroup? Paul?

Paul Tang - Palo Alto Medical Foundation - Internist, VP & CMIO

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Christine Bechtel - National Partnership for Women & Families – VP

James?

Jim Figge – NY State DoH – Medical Director

I want to throw out a challenge question to the panel. As we try to engage patients, I want to make sure that we don't overlook some of our very vulnerable and very complex patient populations in Medicaid.

We've been talking about patients who can access IT tools. What about the patients who can't or don't access IT tools, and what about our complex Medicaid patients with multiple, comorbid conditions, behavioral health conditions, diabetes, cardiovascular, hypertension, and they're homeless? They have alcohol and substance abuse issues. They don't go to Dr. Culman's clinic. They go to the ER. They go to dozens of different ERs. They don't have a medical home. How are we going to engage those patients with HIT tools, and how can we fit that into meaningful use?

Eric Dishman – Intel Digital Health Group – Director Health Innovation & Policy

I have one idea. First of all, study them because we do. The kinds of folks that you're describing are part of the studies that we do. The second I would say is and somebody mentioned it earlier, it was either Neil, Chris, or both, whoever made the comment that we can't treat IT as if it's universal for everybody. One of the things if you don't have it already, it would be really great to have a patient segmentation around IT because then we'll design systems with very— I mean, you can't have an infinite number of segments. You can't design a system that works for an infinite number of people, but there's probably seven to ten, plus or minus three, kinds of patients that we're designing for with varying levels of engagement and varying levels of access. I tried to write about some of this in the written testimony, so a segmentation is really important.

I think the third is, we need to tap into the— I'll just give you an example because it's the best that I know of. Tim Garson, the provost at the University of Virginia, has this really interesting project called Grand Aides, and he is using federally qualified housing center, sort of a liability and so forth, to train grandparent aged citizens in the community to go out and do a lot of the chronic care management for others that no clinician or nurse has time or incentive to actually do.

I think we're going to have to build kind of a care core, if you will, of folks who are trained on using these IT systems to help exactly the kind of folks that you're talking about. I mean, there's no other way to do it. With the president's pen on the healthcare reform bill, we didn't suddenly have a greater number of doctors and nurses, right? We had a greater number of uninsured coming into the system, and with the age wave even more.

If we don't do some creative use of sort of workforce creation and sort of volunteer programs, we have this idea of saying let's – we meet all these retired nurses and doctors and engineers sitting in assisted living facilities. And nurses, I've just met this guy who was like one of the pioneers of IBM in an assisted living facility that we're working with, and it's like, I mean, it's all this untapped potential that we ought to be able to create a national sort of volunteer campaign around and sort of help them help others who don't have access to those. I think there's a lot of untapped opportunity there.

Chris Gibbons – Johns Hopkins Urban Health Institute – Associate Professor

I would also say a couple of things. Trying to do what you're saying, what you're suggesting, which is a real issue, without doing what we've been talking about before, knowing the patients better is almost impossible. In the same way we have to understand, for lack of a better word, normal patients better to build the tools for them, we've got to understand these populations. Having said that, the more work that I do in those kinds of populations exactly, I continue to be astounded by, yes, low-income and all substance abuse, all these things, but the level of access they actually do have. We have to think about different models of not only what patients do with it, but delivering it to patients.

Two examples, two concrete examples that happened to me in Baltimore, I am working with a group. We have a huge problem of pregnant teens in Baltimore, one of the highest in the country, and so we have some projects in that area. And I was in a community group talking about these things, all low-income,

African Americans, poor as poor. And these workers were lamenting how these women have the wrong information. That's why they're having poor birth outcomes. They're not getting prenatal care.

I asked the question, eventually after hearing this long enough, okay, okay. Where are they getting their information, these poor, low-income women? Whatever information they're getting, where are they getting it from? Do you have any idea what they said?

Neil Calman - Institute for Family Health - President & Cofounder

The Internet.

Chris Gibbons – Johns Hopkins Urban Health Institute – Associate Professor

The number one thing that came up that even astounded me, and I was embarrassed because I do some of this stuff, there's a program on MTV, *Pregnant and 16*.

Neil Calman - Institute for Family Health - President & Cofounder

Yes.

Chris Gibbons – Johns Hopkins Urban Health Institute – Associate Professor

That was the number one place. Number two was Internet—and this is an African American group—blackplanet.org and similar sites, and urban radio. These were the number one, two, and three things that kept coming up in this anecdotal study. But, I said, well, shoot. I can have the typical health or public health or medical response, "Oh, you're killing yourselves. You're getting bad information." Or I can say, "They're already going to these technologies. Can we figure out a way to get the right information into these technologies, see if they will still use it, and then will it affect their outcomes?" And so we're writing grants to try to do just that.

And the other side of the coin is, in a substance abusing population, it's another set of problems. We have another project. Who says you have to own one and have it 24 hours a day, whatever the box or tool is, to get a benefit from it? There's this model of health workers and community health workers and other kinds of providers outfitting them with the tools that then they go to the homes and the communities or to the meetings of these people, and maybe an intervention only needs to be delivered three times a week for an hour. That might be enough. Thinking about new models of allowing patients or gaining patients access, not just every person with a box or something like that, will enable us to make some progress in some of these populations.

Scott Mackie – IDEO – Client Relationship Lead

We recently completed a project for the national campaign to prevent teen and unwanted pregnancies, and I wasn't on the project team, but I understand that one of the things that they found was incredibly successful and critical to the success of the program that they designed was that it was delivered in a way that made sense to the community. You talk about the MTV program. Albeit that that's not a nice, well spoken, sort of typical health advert [sic] but it talks about it in a very real way, and that that does two things.

One, it means that people actually will listen to it and will engage with it because it's spoken to them in the right way. But, two, it also means that it, in general, starts to create a better level of trust with the care system because, as I think we've spoken about, people have had a horrendous experience with the healthcare system and with the establishment. And so, if you can break down some of those barriers, then you can start to engage those people. And I agree that actually people are pretty well connected, even in those lower income communities.

Regina Holliday – Medical Advocate

And another vital element, of course, is the caregiving population. Though there are a lot of individuals who themselves can't necessarily take care of themselves very well, but there often is a caregiver provider that is in a periphery of their life, and whether that person is heavily educated or has ..., you know what, you can learn. When you're put in a situation, and it's someone that you love, all of a sudden you find that there are those wells of strength that you can learn more about technology in order to provide care. Part of our job is to make sure that the access is available, so people can do that.

Charlene Underwood - Siemens Medical - Director, Gov. & Industry Affairs

I had a question. There's some debate or some, I think, differences of opinion. At least I discern that relative to this question of usability. I work for a software vendor, and to Scott's point, we actually do those types of processes to develop our software. We engage. We have rapid development processes. We have usability labs, all those types of things.

Vendors are for innovation, but I think we're challenged a little bit, and I wanted you to drill down a little bit further because you're kind of suggesting that's a policy around regulating usability. And I get that immediate like heart stopping thing that says regulation around usability, then that's going to stop innovation, and you just said, no it won't. It won't stop innovation. You need to study it.

But on the other side, we look at the lead times we have, and Paul made the point on urgency of getting this done that if we put regulation around this, that would tend to slow down the process traditionally. So I'd like you to drill down just a little bit more in terms of your thought processes around. I mean, we are for innovation. We are for usability. We are for making this easier for consumers, as well as providers to use as fast as we possibly can, I would think across the vendors, a lot of work in that space. But again, understanding the problem and putting it to the right use and the right tool to the right use is very key to making all of this work. I wanted to push back a little bit on your comment relative to regulation and perhaps or maybe you really weren't saying that, you were saying something else.

Scott Mackie – IDEO – Client Relationship Lead

Well, I think I'm glad you asked the question because it gives me a chance to clarify. I think it's the point around research techniques, as I said. I think often people make the mistake when they think about usability testing that it has to be done with 100 people, and it just doesn't. It needs to be done quickly and deeply with people to start with, and it's only at the later stages that you need these large-scale usability tests to determine it. When you think about it in that regard, I honestly don't believe that the costs of that and the very, very minimal additional time that testing in a deep way with five to ten appropriate people adds to the process will outweigh the benefits. And I'd actually ask Eric to comment as well perhaps on that.

Charlene Underwood - Siemens Medical - Director, Gov. & Industry Affairs

But I was kind of concerned. I think that's often common practice in many development shops.

Scott Mackie – IDEO – Client Relationship Lead

So if you're mandating something that you say you're already doing, if you value that, and I'm asking that it be mandated so that it's universal and is actually built into the process, then I don't see how that would necessarily lengthen the innovation process if you're already doing it.

Charlene Underwood - Siemens Medical - Director, Gov. & Industry Affairs

I would typically say that sometimes when things get written in language, they don't always correspond to that level of concept that you're trying to accomplish, would be our concern.

Scott Mackie – IDEO – Client Relationship Lead

And that was my comment around it needs to be regulated in the most careful and most astute and most human fashion is that it can't be a regulation that adds an additional stack of paperwork that somebody has to do saying that they've done testing in a particular way and in a certain method and things. It just simply needs to be crafted to insure that people are consulted and involved, but not to create the additional burden. I don't have the answer as to how to write that policy.

Eric Dishman – Intel Digital Health Group – Director Health Innovation & Policy

I wouldn't want to be prescriptive about methodologies. I would say, come in and be prescriptive. There are some high level principles that these studies and pilots need to do. They need to be user centered. They need to have participatory design, and they need to use the appropriate methods.

One of the problems that we have here is that we're treating all these information systems and putting them through a randomized clinical trial methodology that was used for drugs because it's kind of the only method that we have. I have been looking for all the evidence base that says fax machines and phones are great ways to interact with patient data, and I can't find that evidence base, right?

Chris Gibbons – Johns Hopkins Urban Health Institute – Associate Professor

Right.

Regina Holliday – Medical Advocate

Right.

Eric Dishman – Intel Digital Health Group – Director Health Innovation & Policy

But somehow we're applying that RCT, that randomized clinical trial mentality, to all these new information systems that come out. It's not that they shouldn't be tested, but they shouldn't necessarily be tested with a large scale clinical trial. This idea I have about 10,000 household cohort is because some of the kinds of things that we want to study like the emergence of Parkinson's disease or the emergence of Alzheimer's are so statistically rare that we need a large sample to be able to sort of test technologies like early detection technologies in an RCT type way.

But a lot of these information systems we shouldn't be treating them like a drug trial, and they could be much more quick and much more iterative. So we want the right user centered method for the right kind of study. I don't know how you'll legislate that other than you'd put some principles in place.

Chris Gibbons – Johns Hopkins Urban Health Institute – Associate Professor

I would also say just quickly, at least from my perspective focused squarely on sort of underserved and low-income populations. It's not so much that, as you articulate, these things aren't done. They may well be done. But it's more a question of asking the right questions and making the right assumptions.

Generally speaking, those who are developing these tools have little expertise, experience, or knowledge of human factors and other things in these populations, and they have to make assumptions about the end user. So those assumptions will not generally or, at times, not be most congruent with those populations. So unless you do it with somebody who either has that expertise or perspective, even and above involving the right people, if you're not asking the right questions, you're still not going to get to the right answers. And so I would agree that finding a way to incentivize the process of doing it better without crushing it is critically needed to build the best—

I mean, look at the demographics of this country. By 2050, non-white populations will be in the majority. By 2042, the working population will be that way. By 2039, the adolescent and child population will be

that way. So we can frame it the other way. You cannot do this and we are hurting ourselves in the long run, so finding the best way to do it is the way for us all to survive.

Christine Bechtel - National Partnership for Women & Families – VP

Thank you. Deven and then Paul.

Deven McGraw - Center for Democracy & Technology – Director

I want to thank the panelists today because this is incredibly informative, and I'm sitting here wishing that I had brought more paper to write on because the input was so fabulous. But the one thing that I am struggling with and I think I want to ask you all to try. I know we have Neil continually involved with us, but we are, as a workgroup, going to be struggling to make concrete recommendations about what ought to be in meaningful use for 2013 and then 2015. We have a very crude set of tools. We have incentives that go only to certain providers in the provider community and hospitals, and they're not huge incentives. They're big, but depending on who you're asking, they're not enough or they're sufficient. At any rate, it's not an unlimited pool of dollars.

From what I'm hearing from the panel is that this is an environment that also needs a little bit of flexibility. What might be usable for one physician practice doesn't work so well with another, and Neil talked a lot about how they sat down and sort of reengineered and talked to their patients, and that's really hard to do in a policy context that needs to be scaleable and responsible to the taxpayer because this is some significant money that's going out. And, at the end of the day, we need to be answerable to how it was spent and whether it was effective.

I think David was pushing on this a little bit with respect to maybe if we looked to outcomes, and that might give people some more flexibility about how they got to point A to point B. We got some recommendations on certification. One thing that occurs me is that some of the innovation and sort of user centered design that we want to provide incentives for, where is the market push for some of this stuff? I mean, some of what we've got built into certification is some pretty basic criteria that we think all systems ought to have. But to the extent that there's still a choice to be made by physicians and hospitals about which system they buy and what is going to work best for them, I'm sort of wondering what ways can we combine the sort of crude tools that we have with market base incentives.

And so I don't know if you're all – you're welcome to respond to my question. I think it's mostly a summary of what I think is the challenge for us going forward. And I would hope, you know, our conversations are by and large public. We would invite you to continue to be involved, as we sort of struggle through thinking about how to take your recommendations and put them into more concrete criteria. Maybe that would stimulate more thinking on your part about ways that we can refine those and try to get them pointed in the right direction. But it's a very longwinded question, but I think mostly expressing that I think the challenge that we have is enormous, but what you've said to us is very helpful, and it's going to take some kind of iterative conversations over time, I think, to really try to get this as close to right as we possibly can.

Chris Gibbons – Johns Hopkins Urban Health Institute – Associate Professor

My thought is, I agree with you. I don't know about the other members, but I personally don't have all the answers. I don't think that we know, but we have some opportunities. We know the demographic shifts in the country are coming. We know 2015 when this rule, stage three is coming. So part of the process is to maybe incentivize doing the studies now that can help inform later rules that you make rather than saying, okay. What can we do today? Maybe that's not the right thing for all of these things. Yes.

Regina Holliday – Medical Advocate

The one thing that I know when I first heard of the funding for meaningful use and incentives that frightened me was the idea of little kingdoms of data. Having had three months, almost a three-month period of five hospitalizations, one of the really horrible things is you build the kingdom again and again and again and again. And it's usually a four to six window, four to six-hour window of building that little kingdom again, and nothing is transferrable.

One of the things you have to think about very clearly is when we are funding the systems that we have some ability to transfer data. We have some interoperability and portability. We need to look at POS systems within business. This is standard. You can switch from company-to-company in business and retain your data. That is not the feeling I get within a lot of hospital settings. When we look at this and how we're going to utilize this system nationwide, that needs to be in the forefront of our thinking because if we can transfer the data, and then we can get the full data download, that is the first step to making sure the patients get good care.

Eric Dishman – Intel Digital Health Group – Director Health Innovation & Policy

Just a very practical suggestion, I think the center of gravity in most of this health IT discussion nationally is still hospital centric, and we know that. This panel is kind of an exception to that, right, but the gravity will swing back to that the moment we let it. If you create some criteria that pulled data types that are unique to other parts of the continuum of care like long-term care, it will start to be disruptive in some good ways that you probably can't anticipate. For example, if your 2013, 2015, it requires those systems to have data types and categories for activities of daily living data, right? They won't know what to do with it because hospitals don't track activities of daily living and longitudinal data types like that.

If you almost just went through all the other parts of the continuum of care and say, all right. Let's choose a data type that's really unique to that and sort of say, okay. These things have to do it by then. You'll start to build from the ground up a more holistic information architecture that allows you to do that.

The other thing I would say is you've also got to come at it from top down. The reason I push for this audacious goal of saying, you know, let's get the president or Congress or the Secretary to set this kind of going to the moon. Well, that's probably not a good metaphor with This kind of going to the moon agenda of an audacious goal of 50% of care to the home and community in 20 years. I don't know if it's 50%. I don't know if it's 20%.

The point is that we set an audacious goal that we're all sort of aiming for, and you need the air cover of something like that, that we're going to be measured and tracked on as a nation if we're going to make any progress. Otherwise, this is going to be kind of a little ground swell movement that, at times, is kind of a knit on the back of the health IT system design for hospitals, which is really where most of the energy is right now, if we're honest with ourselves.

Scott Mackie – IDEO – Client Relationship Lead

I'll add a comment similar to that, which is just simply that I think many of these things that we're struggling with and where the real change can occur is about systemic innovation, so it's not about building the best product because, actually, to Charlene's question, I think the software companies, for example, are trying to build the best products. But it's not about these individual initiatives. It's about how do you connect them and exactly how do you break down the kingdoms of data. There may be criteria that you can see it that reward the things that start to break down those boundaries and make changes to the system as opposed to make changes to the individual products or the individual hospitals.

Paul Tang - Palo Alto Medical Foundation - Internist, VP & CMIO

Sometimes when we're deep in the grasp of the discussion, it helps to step back and make sure we don't do a great job of ignoring the obvious. In Regina's plea about visualization, I'm seeing two things, at least in my head, and maybe I didn't take ... pills, but one is an elephant. And I'm not sure this is an HIT problem that we're talking about. And our discussion may be too HIT focused. The second image I have is 3 million health professionals on a leash, and then, to Chris' point, the other 300 right with them.

We're talking about the \$27 billion carrot over 10 years in a \$2.5 trillion industry per year. Are we trying to figure out what the carrot should look like, how big it is, what color it is, and whether it should add yet one more carrot on there, or is it more important to look at severing the leash that we're all on. I mean, I guess the final question is which one would you put your money on in terms of empowering the consumers and caregivers that you talk about? Is it building a better carrot, or is there a leash that we need to undo? Some examples could be the ... reimbursement system we have, the licensure program, the laws and regulations that we have that Eric talked about, or some of the liability concern and others.

Eric Dishman – Intel Digital Health Group – Director Health Innovation & Policy

The most exciting thing for me in the health reform bill and it's not huge, but are the experiments with payment reform. Every time we go do a study, particularly that involves the clinical team, the doctors and nurses are rightfully skeptical about the technology from the beginning. And it's partly that they don't have an imagination for it, and it's partly that they haven't thought about what that could do and how that would allow them to do care differently.

But then once they've had experience with pulling actual data and trend lines and new data types, they're like, "Oh my, God. I can't not do this for my patients. This is a better way of doing it," but then they immediately go to the reimbursement of saying, "Everything set up in the system doesn't allow me to go use the tools that you have to deliver great quality of care." And I think the nation sort of has this misnomer that every doctor is so obsessed with money that that's all they think about. I think that's ridiculous. But if the entire system is set up to where they don't have the flexibility as a professional to use these tools in the unique ways that different patients are going to need, then I don't know how we're going to move forward.

For me, we need to sort of really work on the sort of reimbursement and giving clinicians the sort of care flexibility to decide where the best care should happen, whether that's in a visit, whether that's at home, whether that's virtually. And so whatever we can do to remove barriers to that reimbursement and to give them the flexibility is fine. I mean, it's going to take 10, 15, 20 years of experimentation, right, and integration into the culture, so we've just got to let them have the flexibility to go do that and the reimbursement is one of the biggest issues by far.

Chris Gibbons – Johns Hopkins Urban Health Institute – Associate Professor

I think I'm a little bit of a contrarian on that issue, and I apologize. I'm going to have to leave right after I speak, but I'll come back so you can kill me later. I'm not running. I think, while everything Eric says is true, I think the focus on payment stifles innovation oftentimes. Because we can't see a way of doctors getting paid, we're not thinking about other ways to do it. We're thinking about innovating within the ways that we already get paid. And I often say in technology or maybe in healthcare practice in general, if we had all the money to do everything we wanted to do today, we wouldn't know what to do. So you've got to know what to do before.

And I always say, if we create value in technology, so it's not about a tool, but if we create the value, I guarantee you somebody will figure out how to pay for it, and so I think it's about building a better carrot. You have to do the other two, but from my perspective, build a better carrot. Know what we need to do. We'll find a way to pay for it. Thanks.

Neil Calman - Institute for Family Health - President & Cofounder

I would just say I don't have great faith in incentives because I totally agree with Chris. I think we have so many places where you've seen sort of pay for performance models, and you're going to pay somebody for doing better diabetes care. Yes, if you get people focused on some little teeny piece of the world, they can probably improve things there. But for the most part, people don't know what to do.

My goal would be to call out the things that are sort of fundamental truths in where we're headed, and to really focus on them because I think they provide the foundation for things to sort of grow from there. The fundamental truths to me are, number one, as I said before. Patients have full, complete, and total access to their information instantly. Nobody is going to argue with that.

I think the fundamental truth of transportability of information so that it can be consolidated and made intelligible is really there. And if we focused on a few of those things as kind of the things that we could call out and say, "We believe in these things as fundamental principles on which all of these innovations and stuff can be built," I think we'd be doing almost as much as we possibly could with the tools that we've been given, which are, as Paul said, are limited tools, but they are tools, and I think if we accomplish those things, we'd be doing really, really well in this part of meaningful use.

Regina Holliday – Medical Advocate

And I loved your visualization, and I, of course, am more of the let go of the leash group. As an e-patient, we are doing what we're doing without pay. We do it every day, day in, day out, and our goal is just better patient care. And we can work with the medical community to provide that. So that, with transferability, with access, if you just have those things and let the leash go, we can just change the world.

Christine Bechtel - National Partnership for Women & Families – VP

I'm going to let Regina have the last word on that because how can you, but please join me in thanking our fabulous panel today.

Paul Tang - Palo Alto Medical Foundation - Internist, VP & CMIO

Thanks as well. The challenge is for panel two and three to have to follow panel one, but it really was a stimulating discussion. It just opened up a whole lot of thought provoking questions and challenge to the group to try to either unleash folks or to change the character of the carrot.

Our second panel is going to talk about patient generated data, and this is how can we take advantage of it. How can we use the levers that we have at our disposal to recommend to ONC to further the use of patient generated data? This panel is going to be moderated by David Lansky.

David Lansky – Pacific Business Group on Health – President & CEO

Thank you, Paul. I'll give everybody a minute to try to get settled, and maybe take a stretch break if anybody wants to in the back or in the front. Why don't we take a two-minute break and try to reconvene in two minutes because I think we are.

Let's see if we can reconvene, and let me begin by thanking our panel for coming today. Like the previous panel, this is a phenomenal group of people who devoted their careers and lives to improving healthcare and to innovating. Obviously the focus of our next panel from all of you will be how can the healthcare system take advantage of patient and family and caregiver knowledge, expertise, experience, in improving the whole care cycle, and how can HIT be a medium for doing that. You've all done phenomenal work, and we're just inspired by what you've done and glad you're able to join us today.

Let me just do a very brief introduction, so we can spend most of our time hearing your suggestions and insights. Dr. James Ralston from Group Health Cooperative in Puget Sound has been a just phenomenal leader in chronic care management and in health IT and in bringing those two together for many years. As hopefully some of you have seen in prepared material, some of the publications Group Health has done based on Jim's work in diabetes and hypertension management in particular, taking advantage of direction connections to patients. And Group Health has, for a long time, been a leader in the EHR adoption and use. And, as a cooperative model, we appreciate the governance approach to include patients directly in the healthcare system. Thanks, Dr. Ralston, for coming today.

Patti Brennan from the University of Wisconsin has been a tremendous leader, and I, personally, of course, remember her photographs of the refrigerator and the dog kennel as models of ethnographic approaches to thinking of how patients make decisions and manage their health. Patti has also been a leader in the Robert Wood Johnson funded project health decision program, which has really been innovative in thinking about how to understand patient's use of technologies to improve their health, so thank you, Patti, for coming here and all your leadership.

Carol Raphael has led one of the nation's largest home health agencies, Visiting Nurse Association of New York, and has become a great leader in New York State of health IT and health information exchange. And really, I think, a model for, as some of the previous panel members suggested, using health IT in settings other than the doctor's office and hospital to really fully engage the patient and home in provision of care and using health information exchange to do that. Thank you, Carol, for being here and for your leadership.

ePatient Dave here in the analog version, I think many of you were exposed to a really remarkable exchange that was stimulated by Dave deBronkart's examination of his own health records when they began to be exchanged through personal health record portals, and that stimulated a live experience on the blogs and elsewhere about the opportunity for patients to understand and correct and enhance their information in what we all can do in the various systems to manage that information better. Thank you for coming here today.

Dave Whitlinger previously had a career directly involved in developing the standards for mobile health applications and information working with many of the vendors around the world to do that and provided great leadership to all of us to understand the opportunities for mobile health and now is working in New York State with the New York eHealth Collaborative to guide the very substantial investment New York has made in e-health and health information exchange. So I think both of your perspectives in the continued experience and the health information exchange experience will really be valuable to our discussion today. Thanks for being here.

Hank Fanberg with Christus Health has been a leader for many years in thinking about how can a large delivery system engage their patients in many settings, including using the new mobile technologies for that. So again, thank you all for being here. I think your written testimony was fantastic, and I'm sure we'll have many questions, but I think we'll just go in order as you're sitting, and welcome your oral presentation for the quick five minutes that you have, and please keep an eye on the timer, so we'll try to stay on track. Jim?

James Ralston – Group Health – Associate Scientific Investigator

It's a real honor to follow up this morning's great panel. I applaud this workgroup's current deliberations and thank you for the chance to share with you Group Health's experience with incorporating patient generated data into our electronic health record. Group Health is a nonprofit, member cooperative health

system that integrates care with coverage. Group Health cares for over 380,000 people in Washington state and tries to keep patients at the center of everything it does, including its health information technology.

Over the past six and a half years, Group Health has directly engaged patients with its EHR through its patient Web site My Group Health. During this time, patients and providers have done more and more communication online over the Web site. As of December 2009, 59% of Group Health enrollees have accessed their shared electronic health record online. And one-third of all our primary care encounters are through secure messaging over that Web site.

As more patients engage in care online, patient generated data is becoming an increasingly essential part of care at Group Health and part of our EHR. The health profile, our online health assessment for patients, is a good example. To provide detailed and personalized health assessment, the health profile uses 250 questions on topics including preventive care, chronic disease management, and healthy lifestyles. The profile also gathers patient information relevant to care and doctor/patient interactions, including patient's living circumstances.

After completing the health profile, patients receive a report on the patient Web site, and the primary care team receives a report within the electronic record for clinicians to use in delivering care. The EHR and the health profile exchange discrete patient data to support more robust health assessments and better documentation. For example, discrete data fields from questions in the profile such as past medical history, surgical history, and social history details are automatically transmitted to the corresponding fields in the EHR. The profile also pulls data from the EHR such as patient's latest cholesterol test results to help calculate health risks and make clinical recommendations. This two-way data integration with the patient's EHR significantly enhances the value of the health profile's assessment.

Separately, we have also found that data from home monitoring devices is important for improving care of patients with chronic conditions, including those with high blood pressure and diabetes. We published two randomized trials using the chronic care model and data patients entered into our EHR. In our 2008 study in JAMA, we showed home blood pressure monitoring, plus secure electronic communication nearly doubled the percentage of people whose blood pressure was controlled.

In our 2009 study in diabetes care, we showed home glucose monitoring with secure electronic communication improved glycemic control in patients with Type II diabetes. Both of these studies required inefficient workarounds to get patient's blood pressures and blood glucose levels into the EHR and then viewable for collaboration between patients at home and the providers in the clinic. Being able to incorporate this patient data from home blood pressure and glucose monitors into the EHR would have substantially improved workflow in the trials and speeded up spreading those interventions into usual care.

Although patient entered data are important for using EHRs, they will be meaningful only if we can keep the needs and preferences of patients first. To do this, we should set measurement of patient experience as a high priority criterion for meaningful use. Our April 2010 health affairs article showed how regularly surveying patients about their experience with online services of the EHR was key to Group Health's continual improvement of its health information technology. So policy support for patient entered data should start with measuring patient's experience with care involving EHRs. Meaningful use should then consider specific patient entered data to meet patient's preventive and chronic care needs. These data should include patient's individual health risk and history information, and select data from home monitoring devices such as home blood pressure measures and blood glucose levels for patients with

diabetes. All of these data should be visible to patients and support ongoing collaboration with healthcare providers. Thank you.

David Lansky – Pacific Business Group on Health – President & CEO

Thank you. Patti?

Patti Brennan – UW-Madison – Moehlman Bascom Professor

Thank you very much. I want to thank the committee for their focus on this important theme, and I want to particularly thank Judy and Josh for their work in getting this together and for the repeated e-mails from me. Thank you.

I also want to thank my project team in Wisconsin, the Project Health Design team. Gayle Castro is our deputy director. She's sitting here at the table with me today. They help put together the remarks that are presented here today. And I want to thank the large number of people in the audience who are here thinking about the same concerns that we all have.

Project health design, which I'm the project director of, is a national program on the pioneer portfolio from the Robert Wood Johnson Foundation. This initiative is designed to rethink the power and potential personal health records, to move us from the idea that personal health records are a data bucket, to the idea that personal health record systems are a platform for action. Importantly, we need to think about data flowing from many sources mediated through perhaps a third party data aggregator, and used by a number of applications that are patient facing and useful to the individual.

Now I have the ability to speak here today because we've had 14 teams around the country working with over 500 patients over the last 3 years trying to understand what is health in everyday living. I'm here with one simple message for you. Patient generated data is more than clinical data captured in the home. Patient generated data is information about the patient's experience, the person's experience. Regina pointed out in the first panel that it is the experience of living that the person is the expert in. The clinical science and symptoms are the purview of the professional.

Our focus on Project Health Design, in listening to our participants, has been on health and everyday living. But patients want to define what kind of data is really necessary to capture health in everyday living. We call these observations in daily living, and they're highly idiosyncratic. They're cues that individuals use to understand how they are feeling, to know how the tenure of the family dinner conversation might affect glycemic control later in the week, to understand the relationship between air temperature and pain experienced. These are indicators used by patients to activate for action.

They have many information technology needs. We're trying to respond to those in Project Health Design. We need unobtrusive data collection mechanisms, including home based sensors and environmental sensors that unburden the patient in learning about self. We need interesting and informative displays of that information to patients, as well as their care providers.

We need recommendations for action. Some of the data patients place their action on, frankly, isn't the best we'd like them to be thinking about. We maybe want them to be more accurate. We need to help to bring these together. And we need to know more about actionability than reading, so we have to think about platforms for action, not only that what will be displayed for an individual, but alerts like maybe even messages sent to the clinic ahead of time that the patient may be calling in.

Observations in daily living can be incorporated into the clinical care, and this is the focus of our current Project Health Design activity. We think that person specific alerts that bring an individual into action for

care, that make them think to call the clinician or exercise more might be critically important for the clinician to know and can be easily brought in, in conversation, as well as in electronic form.

We believe that observations in daily living may ... very systematically with the signs and symptoms that clinicians are more familiar with. And we believe very much that understanding observations in daily living may help clinicians know why therapies are or are not working. But there are problems incorporating observations in daily living into everyday clinical practice.

First as mentioned earlier, the workflow problem. When do they come in? Second, the volume problem, the tsunami of home based senses could drown even the best industrial engineer or nurse in trying to figure out what's going on with the patient. So we need high level information tools that help us synthesize and visualize data. Finally, as James noted, we need to be able to break through the wall of EHRs so we can send data from the household back into the clinical record in a trustable and secure fashion that can be integrated into care practices.

I'm going to leave you with three recommendations of how I would like the health IT policy to address meaningful use of health IT and where a person generated observations in daily living can be helpful. First, we ask for technologies and policies that enable information selected and gathered by patients to be brought into care. That may require changing regulations, understanding liability differently, or training clinicians and nurses differently to figure out how to interpret health in everyday living and incorporate it to care.

Second, we need to provide health information in a computable form. It's not enough to send an electronic facsimile or a PDF of a person's medical record to them. We need to have actionable, computable information accessible and available to the individual. The distributed models of information technology will overtake the healthcare IT models, and we will move to a new system of information.

Third, we need information that is actionable. It's not enough to dump data on a patient and say, guess what's going on with you. We have to help them understand and interpret that.

Finally, I'll close with two requests: a new research agenda that helps to achieve these, and changes in the marketplace that stimulate infrastructure, product development, redistribution of financial incentives, and technological solutions to the challenge of health data. Thank you very much.

David Lansky – Pacific Business Group on Health – President & CEO

Thank you, Patti. Wonderful guidance for us. Appreciate it. Carol?

Carol Raphael – Visiting Nurse Service System – CEO/President

Thank you. I want to first of all thank the committee for the opportunity to address the very important issue, how to incorporate patient generated data in meaningful use. At the Visiting Nurse Service of New York, very briefly, we see 30,000 patients every day in 30,000 different locations, and we also run two health plans that are very unique because they are for people who have multiple chronic conditions and often functional impairments. And our patients are characterized by having not one chronic condition. That's rare. They have three to four chronic conditions. On average, they take 8 to 10 medications, some up to 19 to 20 medications, and have, on average, 5 to 6 functional impairments.

I think we're also characterized by having a very multicultural population. We speak 36 different languages, and 1 out of every 5 patients we admit is Hispanic. And we also are very representative of what's happening in the nation. Our oldest patient is 108, and we have 250 patients over 100 years of age.

I have three recommendations based on our experience with our electronic health record to share with the committee today. First of all, I really do believe that, from the outset, systems have to be designed to do what I call the three E's, to engage patients, to educate patients, and to empower patients. When our nurses go into a home, they sit down with our electronic health record, and they share something called my action plan. They go over the chronic condition. And I think Regina will be happy. It is animated. We're not Pixar, but we're pretty good at our animation. And after we go through all of this, we test our patients on their competency and whether or not they've understood any of what we have done.

We then spend a lot of time on medication. You would not believe what we find in medicine chests, and we try to combine it all, and then we go through the medications. What's the dosage? Do you take it before a meal, after a meal? What is this for? And does this make sense to you?

I think that we really need to think also in designing systems about having open-ended questions. We often ask patients, "Why do you think you were in the hospital? What are your goals?" And their goals, remarkably enough, are not at all like our professional goals. Their goals are to make it to their daughter's wedding in June, or be able to get to the supermarket without being out of breath, and we want to chart how they are doing against the goals, as they articulate it.

The second recommendation, in large, the meaning of patient. Paul and I sat on the Institute of Medicine committee where both of us struggled mightily to include informal caregivers in the definition of the workforce. It is inconceivable to me that we could do palliative care in hospice without involving the family in the care team. It is inconceivable that we could be taking care of a six-month-old who just had a heart transplant and not involve that child's family in the care team. So I really think you need to enlarge what you mean by patient and change the unit of service.

Thirdly, this is my pitch, I think we need to think about where we're going, not where we are, and I do applaud your having incentives for meaningful use for hospitals and physicians. But we, as a home healthcare and long-term care and chronic care provider are left out of the equation. We bring home 5,000 patients from the hospital each month. We are working on transitions. We have been able, through partnerships with physicians and hospitals, to bring down readmissions by 4% over the last year.

A patient gets an instruction. Eat a salt free diet. Do X, Y, Z. You see a week later they are eating what they have always eaten, and their blood pressure has taken off. Low and behold, they're going to end up back in the ER. So a physician may see someone for 10 or 15 minutes. Someone may be in the hospital for four to five days. We are with patients in a continuous healing relationship 365 days of the year in the center of the patient's universe, their home. So I really can't envision a system in which we are not part of the interchange of information and the ability to work as a team across many sites. Thank you very much.

David Lansky – Pacific Business Group on Health – President & CEO

Thanks, Carol. Very helpful. Dave?

Dave deBronkart – Society of Participatory Medicine – Cochair

Thanks again for the committee for helping me be here. It was a year ago this month that Paul and I found ourselves on the front page of the *Boston Globe*. He was quoted in the article about what happened when I decided to get engaged with my medical records. And it's hard to believe that that was just one year ago, but here we are.

That was an Alice in Wonderland experience for me. I fell down the rabbit hole, started discovering there were an enormous number of things that somebody with no medical training or expertise, thank goodness I now see, could see as ways to improve the system. In August, I went part-time in my day job, and now I'm completely out of there. This is what I'm doing. Spread the word. I'm looking for work.

Seriously, it's become really clear to me that the conventional wisdom of how to make healthcare better should just be thrown in the dumper. It's time to take the car keys away from the people who have been failing for decades. I respect their expertise. My life was saved by great medical people. But the policies and practices that the industry endorses, for instance, there was just an ad I saw yesterday from the American Hospital Association urging CMS to take an incremental approach. I mean, give me a break. How do we possibly?

I say nobody ought to be having any voice in this game unless they have a shared priority to do healthcare better. Anybody with any other priority ought to just be shut out because we have a crisis. We have this urgent financial crisis. I don't need to tell you the numbers.

So we've got this huge growing need, and we've also got an enormous number of innovators who would love to help, but what's keeping them apart is that the innovators can't get at the data. So they can't, like, do the job better. One of the key things, I think, I mean we obviously need a lever, and I see two big levers available. One is let patients help, as people have been saying. And that means getting at their information because, as my doctor, Danny Sands says, how can patients participate if they can't get their hands on the information? Then also, letting innovators into the game.

Doc Searls, the Linux and open source guru, after his own medical disaster a year and a half ago, proposed patient as platform. That the patient ought to be the point of integration for information, it ought to be not acceptable for the information to live in and be the property of the provider. And I mean, in practice, as well as in principle. I think we ought to require that in order to qualify for meaningful use, the provider must not hold onto the data and prevent others from leveraging its value. I think this is a policy move that we can make that would be potent.

Think and look, listening to the discussion, a question about policy in the previous panel pretty much dumps the rest of what I was going to say here. Here are my suggestions for policy. Two things in the area of ownership: We can declare one way or another, that the patient owns the data. It is theirs to do with as they please. I'm not a legal expert, but I understand that it's not clear that this is, in reality, the case. Take it where they want. Disclose it to people they want. Block others from seeing it. Then this business of no stimulus money, no incentives without sharing, an open API, I think, is essential, as my written testimony says. Tied into the patient owning the data, the idea of having it being user-friendly language would be great.

Two things in the category of facts and evidence: I think we ought to do what my hospital has been doing, Beth Israel Deaconess, which is track and publish harm. Paul Levy has talked to the hospital association last week said, let's call it what it is, killing people. How many people got killed in this hospital because of mistakes that shouldn't have been made? Now that's unpleasant, but you know what? I'm tired of denial. I'm just tired of denial. Let's agree that there's a problem that needs attention.

Fund studies for patient engagement methodologies, some pilot projects. Two suggestions in the way of rectifying awareness: Number one, HIPAA training, both for patients and for medical staff to get people's heads right about what the current law is. Notice, I'm not talking about changing any policy there, just making people aware. Then some patient engagement training, letting people know that they can ask, that they can speak up, that they can ask for their records and so on.

Then, finally, shifting per Eric Dishman's idea to having lots more care being done outside the hospital system. First, moving to the patient centered medical home. I love the evidence that PCPCC's pilot programs have been developing. Last month I participated in my hospital's annual Lean quality improvement retreat, and I learned about the Lean methodology. And a key part of that is having everybody work at the top of their license and not spending their time doing things that less scarce people can do. We're doing a poor job of that. We need more primary physicians, so shifting to medical home and then to the home. All in all, I think what it comes down to, as I said on the cover of my testimony, the resource that's most often underutilized is our patients, so let patients help.

David Lansky – Pacific Business Group on Health – President & CEO

Great. Thank you very much, Dave. Dave Whitlinger.

David Whitlinger – NY eHealth Collaborative – Executive Director

Good morning, panel. Thank you for allowing me to participate today. I'm honored to participate in the conversation that we're engaging in. As relayed, I'm the executive director now of the New York eHealth Collaborative, affectionately referred to as NYeC ("nice"), which is a nonprofit, public/private partnership between the Department of Health and the healthcare stakeholders within the state of New York. I'm also pleased to see several board members, the Department of Health here. It seems like we have several moles in your presence, and we're pleased with the output that has generated so far.

Additionally, we are, of course, recipients of a state HIE grant. We're one of the recipients of one of the REC grants for the New York State. We have significant support from the Department of Health. Summed up, New York is amassed around \$150 million over the next 3 years for the development of health information capabilities within the state. And it's from this vantage point that I'm addressing the committee today, and it's from this vantage point that our organization is looking to pull together all the stakeholders within the state in order to interpret the meaningful use that eventually comes through the pipeline here, and we're in the midst of assembling our strategic plan for the state. I'm very looking forward to the output of these discussions that will hopefully impact and reflect upon what we will do in our strategic plan.

Again, thank you for the opportunity to participate today. I think that it's a very meaningful conversation. Because I submitted my testimony at a late date, I also had the opportunity to read all of the other testimonies prior, and I had an opportunity to cherry pick and not be redundant. So let me choose a few key points and talk to them at a little bit more depth.

First, to the point of patient engagement, I thought it would be interesting to introduce into this framework the incorporation of frame or a segmentation of patient engagement, and this is somewhat versed in the background that we developed through the continue ... health alliance and working with PHR vendors. As you are well aware, a population of healthcare consumers could be divided into two simplistic segments, and we could call those well and the chronic. And those that are well account for roughly 80% of the population, approximately 20% of the total expenditures are healthcare. Those that are chronic, of course, account for roughly 20% of the population and approximately 80% of the healthcare spend.

Obviously these are two different segments of healthcare consumers. They have two dramatically different needs from their healthcare system. It might be interesting to start to frame a conversation about patient engagement because of those two ends of the spectrum. They are two vastly different, of course, in how they might want to consume healthcare services and interact with the healthcare system.

Generally speaking, the well, of course, are infrequent users of the specialty care and hospitals. They predominantly see their primary care physician or the equivalent. And, for the most part, they don't have a large number of different physicians that they see. They don't have a large number of ailments. They don't need "collaborative care" to the degree that their counterparts might.

For the goal of most of the healthcare, we might be able to characterize as prevention through the promotion of healthy lifestyle, early detection through screenings, and the management of potential risk factors: smoking, diet, activity level. If you look at the PHR systems that are trying to make it in the retail market today, this is one of the user experiences. This is one of the sets of devices that they're trying to incorporate. This is one of the ends of the spectrum if you are where the PHR market is trying to address, and that's prevention, promotion of healthy lifestyle.

The chronic, of course, on the opposite end of the spectrum, are frequent users of primary care, specialty care, hospitals, wide range of diagnostic tools, labs, imaging. They are, as we've heard through many of the panelists earlier today, carrying around large volumes of health data. And they do need help, of course, to manage that data, and that is, again, where the PHR systems and companies are looking to try to address.

Perhaps we would look at how the healthcare system, and their interactivity after they're discharged from their health system and they're back in their home. Perhaps that's the goal that the provider's organization might have is some sort of measured compliance with that treatment plan. They're discharged with a treatment plan that includes their medication. That includes perhaps capture of vital signs. That includes return visits to the physician organization that discharged them. Perhaps we could look at that compliance to their treatment plan as a goal or measurement tool, and perhaps we'd look at the evidence provided from the feedback of the patient and through those periodic labs as a measure of that.

Obviously, as I said, these are simplistic bookends of a spectrum. There's obviously a full spectrum in between, but this might be interesting ways to define some of this patient engagement in order to have some more collaborative or deeper conversations with regards to consumer engagement.

Some of the things that we might talk about here, obviously the individuals that have chronic, have a large volume of data, and that chronic care model looks to try to be a collaborative model. We have many different physicians that are trying to participate in that care model. What we perhaps look towards ending up with is something that is very now commonplace in the business community: collaborative tools on the Internet where many different types of professional organizations can collaborate on a given project. The project, the patient, we need to collaborate together. There are tools out there that do this in a business world. These tools could be readily, perhaps with some of the innovators that were in the previous panel, brought to bear on that collaboration of care model.

Of course, some of the problems that we have to overcome have already been discussed with regards to access of the data, interoperability. These are not easy problems. I believe I'm speaking to the right people that are here to solve those problems.

Let's talk a little bit about the individuals that are well because I think that they've been underserved in this whole discussion, and just for a little bit here. We see that those individuals that are well, obviously they have less healthcare data created by the providers or less likely to create their own healthcare data. They're not ones that are likely to be very interactive with that healthcare system unless instigated to.

This may be to David Lansky's question to the previous panel. It might be an interesting thing to look at, well, what is that interactivity engagement? One of those might be the preventative screenings. If primary care, if those doctors that are doing electronic health records, in trying to implement those in a meaningful way, if they were challenged to provide timely screenings for the preventative care models or the preventative care screenings and the risk factors around the health risk assessment, perhaps that would be a good measure to try to get those patients engaged because clearly their health conditions aren't such that they are demanding that.

Just one last point I'll make because I know that I'm over time. An interesting source for talking about these homecare elements of data, something that we learned from the continual health alliance, we had very, very strong pushback from the physician community when we started. There was a strong resistance to this home data, and being incorporated into their electronic health records. It was dirty. It was not data that had been created by a professional, and they didn't know whether or not the devices that were creating the data could be tried and relied upon.

The way we got around this though was that we created, within the standards framework, the ability to tag that data, not only from where it came from, where its location, where it was generated, but also the quality of the device, was it an FDA regulated device, or was it a low cost weight scale that was bought at a convenience store. So being able to tag the data with where it came from and its data quality allowed those physicians to have the trust that when the data eventually percolated up to their electronic health record system, they'd be able to make the judgment of whether or not to trust the data. And, at that point, they were very, very receptive to usage of these devices in home healthcare. So I'd also offer that that might be something to think to incorporate in the future standards setting. Thank you for your time.

David Lansky – Pacific Business Group on Health – President & CEO

Thanks very much, David. Thanks for being here. Hank, last

Hank Fanberg – Christus Health – Director of Technology Advocacy

Well, I'd like to thank the committee for inviting me today. I'm Hank Fanberg. I'm the director of technology advocacy for Christus Health. And I'm going to speak to using patient generated data specifically around preventing readmissions to the hospital. But before I do that, I'm going to start with my summary.

Number one, all of us; we come with particular context of how we approach health information technology. I admit that I have that hospital context, but also understand that patient generated data is critical, but we need to have the standards in place so it can be utilized by those that are going to use it, i.e. the clinical care team. Having standardized data that can be manipulated is critical.

Number two, it's about relationships. The technology is a tool, and we can't lose sight of that. Number three, we can't lose sight of the social and economic implications and issues that everyone has. Number four, it's ultimately about changing behavior. What are we going to do with all this information? We're collecting it. We're doing something with it, not just to put it into a data repository, but to change behaviors. And, as we know, behavior is a little bit difficult to impact from time-to-time.

First, let me just give you the lay of the land with Christus. We are a Catholic, faith-based, not-for-profit healthcare system. We operate in eight states. We have 350 care sites, 40 hospitals. The majority of our hospitals are in Texas and Louisiana, and you may be familiar with that part of the country as also being called hurricane alley. Three of our hospitals were ground zero for Hurricane Rita. As a New Orleanian, I have firsthand experience with Katrina, and the Markle Foundation did some outstanding work around why we're all here today, why we have to have this health information available when

something like that happens, some type of natural disaster where people are scattered far and wide, and hospitals are closed, and care is not available.

But from a philosophical standpoint, Christus believes that healthcare takes place in the community. It doesn't just take place within the walls of our hospitals. And, as such, we need to be able to reach out to the individual wherever they may happen to be, and sometimes that means they have to be admitted to the hospital. And when they are admitted to the hospital, we want to make sure we have the right information, as much information as possible. And when they're discharged, we want to make sure that they don't come back.

But we also know there's a recent study published in the *New England Journal of Medicine* that roughly 20% of people, discharges are readmitted to the hospital for a variety of causes. Not all of them are not planned, but of the ones that are not planned, the majority of the reasons why relate back to a chronic condition and the three big ones, diabetes, COPD [sic], and congestive heart failure. So we also have an aspect of keeping people out of the hospital that relates directly back into where they are because once they get discharged, we need to be able to connect the dots of all the locations that they happen to be and collect that information.

It also means that we need to be educating the patient, and others have talked to that before. So how exactly can we do this? Well, we're already using health information technology that's doing some of this already. If you think about the medication management that goes on within a hospital setting, we're already doing that. We're already providing patients that are discharged and go home with the remote monitoring device so that they can use at home, so the care team can get the data and collect the data. But there's not just one overriding aspect to it. There are multiple aspects to it.

Could we do a better job? Sure. And we're working on doing a better job. The electronic discharge, which we're trying to make sure that follows the patient, the education can be delivered electronically. But it also gets back to that relationship and to making sure that the individual understands what's expected of them once they've given the instructions, and to provide the instructions to them in a manner and a methodology, which they like and they are open to hearing. And the previous panel spoke about that, so I'm not going to speak much more about that.

What I would like to point out is in conjunction with the discharges and frequent flyers; we instituted a program called care partners. Basically it's community health workers, and without using a whole lot of HITECH, we went into the EDs. We identified the frequent flyers. We also took a look at their hospital admit, how many times they were admitted, very higher users, but pairing them with a community health worker who is there to help them with all of the non-clinical aspects of care.

With 400 different individuals, now we've been able to reduce utilization of the ED by 16%. We've reduced hospitalizations, readmissions by 35%, and we've reduced the cost of care by 43%. So there's a tremendous amount of value. There's a tremendous amount of work that needs to be done. We need to make sure that the individual is involved. We're collecting data from them. We're just starting down that road, but there's a much, much longer way to go.

My last comment, recently the FCC put out a national broadband plan. There's a chapter in there on healthcare. If you haven't read it, I would suggest it very highly. That's the other piece of it. If we're going to talk about electronic tools, we need to make sure people have access. Frankly, with a lot of our populations, we found the cell phone to be the best way to reach them. And the new national broadband plan speaks to some of that. It talks to some of what we're here about today, and I would urge you all to read it. Thank you all so much.

David Lansky – Pacific Business Group on Health – President & CEO

Thank you, Hank, and thank you to all of you for giving us your time and expertise. Let me just start off with a kind of overall question, and obviously we'll all chip in. I heard two themes come out of your testimonies. One is how do we capture information from patients into the systems, which will then be available both to patients and families, caregivers, and to professionals. And secondly, how does the information then get used to influence care delivery and outcomes?

Starting with the first question of how do we capture it, which is in effect the theme of stage one of meaningful use that's already pretty well underway. And now we're looking at 2013 and 2015 and sort of catching up with the patient and family and caregiver provided information as part of HIT environment.

I heard a little bit of tension existing on a couple themes. One is a couple of you mentioned your vendor's existing software platforms don't make it easy to capture information from the patient. Another theme is some of what we're going to capture from the home and the patient and the family is less structured than the data we are now capturing in the clinical setting. And the standards haven't yet been articulated for a lot of the data coming out of the person's own experience. Yet, Patti, you and others emphasized the importance of capturing data in standard, machine readable, interoperable ways.

As you look at our challenge of, let's say we have the job of the 2013 meaningful use specifications and certification criteria. What's the most realistic step we could take in the next two years or four years, either on the certification vendor side, product side, or on the incentives for capture of data from the non-institutional setting that you'd recommend to us to address the capture problem? I'll just go down the row if any of you wish to speak.

Patti Brennan – UW-Madison – Moehlman Bascom Professor

I'd like to begin addressing this. I would like to have, as a principle, that you could make actionable a number of different ways that security should be tied to the data elements and not to the data storage sites. So there's a great emphasis on interoperability of data, but we presume that the data are wrapped in a secure locker somewhere and this will require engagement with the computer science community. It's not something I think we can do in the health community as well. But security needs to operate at the level of data, and that's both technical security as well as security policies.

Second, we experimented in Project Health Design with a common platform, an operation data integrator similar to what we now are seeing in HealthVault and Google Health. And, within that, we developed data specifications, the data model for observations. I think, in two years, we're not going to have the language of observations. I'm not sure we'll ever have the language of observations, but what we may have is structured formatting to be able to capture the observations and organize them in ways that may be differently organized for patients than for clinicians. So security should follow the data element and data representation tools can begin first in a non-semantic structural form.

Carol Raphael – Visiting Nurse Service System – CEO/President

I was going to say that I think we need to figure out a way to capture and report on the patient experience. I read Neil's testimony, and I thought there was something in there that was particular apt, which is, I mean, we often say that quality is in the eye of the beholder. And we think we've done a terrific job technically and the patients had a dreadful experience. And I think, somehow, we need to capture that patient experience, and it has to be factored in, in how we think about meaningful use.

David Lansky – Pacific Business Group on Health – President & CEO

Carol, let me press you on it. Would you imagine that it's appropriate for there to be a single national standard in the next two or four years of what we capture and how we capture it? Or is it just conceptually we should create a pathway for that to happen?

Carol Raphael – Visiting Nurse Service System – CEO/President

There's a lot of work being done now on publicly disclosed sort of quality indicators, and I think the domains have kind of been in, I would say, a triangle: one angle being the processes of care, the second angle being the outcomes, and increasingly the third angle being the patient experience. So there is a lot of work being done to standardize and be able to benchmark what is happening in regard to the patient and family experience. And I'm wondering if in some way we can build on that rather than have to create something entirely new.

James Ralston – Group Health – Associate Scientific Investigator

I'd like to echo that the patient experience, I think, is critical if we're going to do patient entered data. There are some instruments out there being developed. CAPS, we just finished a pilot of a CAPS instrument that included HIT experience around specific service domains for online engagement, so around messaging, refills, visit summaries, and test results, so kind of the big four hitters that we get in engaging patients so far. It's just the beginning, I think, of services that are going to be meaningful for patients, but CAPS has taken a lead and said these look important. If we can marry those measures of good experience of patient engagement on a line with evolving measures of the patient centered medical home, I think that will be an excellent start. I think we're not looking for the complete answer. We're just looking for a start.

But, for instance, if you're going to measure patient messaging or patient messaging is going to be part of the meaningful use criteria, I think we need to measure the experience of patients. You can have a good messaging experience, or you can have a bad messaging experience. And I think if we're going to incent on it, we want to make sure that we have a meaningful outcome for that criteria.

David Lansky – Pacific Business Group on Health – President & CEO

Could you say a little more? You mentioned in your written testimony the vendor challenges and you mentioned the workarounds you had to do in your chronic care project. What advice would you have for us that we can signal to vendors, ways of making it less difficult for organizations like yours to do those things in the future?

James Ralston – Group Health – Associate Scientific Investigator

There's no good place for the data. I think, as mentioned earlier, it needs to be flagged as patient entered data, and it's not because it's less quality data, but it's different data. For instance, if I'm looking at home blood pressures from a patient, I will give those a lot more weight if I've talked to the patient about it and we know they have a good monitor. I give those so much more weight than I give the measures that they're getting intermittently at office visits when they may have pain or the circumstances may elicit white coat hypertension. But there's no good place to flag that in the record, so we've had to create workarounds to be able to get any of those blood pressures in, and we don't have an easy way of visualizing those separately from the blood pressures and other data they get during clinical care. If we had those, it would be so much easier to make good clinical decisions.

Another example is blood glucose monitors. We have patients that type in their blood glucoses into secure messages, and that's a lot of data. Other times we have patients come into the clinic with their blood glucose monitors, and we print out with the software that the glucose monitor device company has. We have that visually for the patient and provider, but there's nowhere in the record for that to go. So it's not just online engagement that this information from patients is coming, we need to get it into the record.

We have it every point of care, whether that's in person, over the phone, or online, so if there was a place in the record for some of these key elements for decision making, it would make a big difference.

David Lansky – Pacific Business Group on Health – President & CEO

We'll keep going down the row here ... is up, and then we'll come back to our questions here. Dave?

Dave deBronkart – Society of Participatory Medicine – Cochair

I just want to point out regarding this issue of the quality of home data. There's this fantasy, I've discovered, that the data that we gather in doctor's offices and in hospitals is of high quality. One day when I was in my hospitalization, I was weighed three times in the same hospital, and there was a range of five pounds in my weight. Now my point is – what was it? Somebody said something earlier, like what's the evidence that faxing data around is good. I think we ought to wake up and not presume that anything from outside this industry that's disfunctioning is more questionable than what's happening inside it.

David Lansky – Pacific Business Group on Health – President & CEO

Dave, do you have a comment?

David Whitlinger – NY eHealth Collaborative – Executive Director

Yes. A couple of things to react to: One is, and not to perhaps jump to the conclusion of what the standards should be set, but there has been quite a bit of energy put into the device industry over the last couple of years, the IEEE 11073 set of standards, a couple of transport standards, USB and Blue Tooth that were all rolled into the Continua Health Alliance guidelines. So the device set of standards really has a fairly rich opportunity for you to tap into, and the device manufacturers are really starting to move in that space, and it does trickle all the way up through those set of standards all the way to the EHR level. The other data that perhaps that might be considered less analytic data, more subjective data that there might need to be a lot more work put into how to standardize that from the home perspective.

The other thing that I think is an interesting piece of conversation is what is the intermediary weigh station, if you will, before this data is accepted into the clinical system. The PHR programs are trying to be that today. I think that some of the EHR vendors have exposed a PHR like intermediary position for this data to weigh and wait for disposition by a clinical care provider, a clinician who can look at the data, determine whether or not they think it's valid enough to incorporate into the electronic health record.

I think we should think about whether or not that's the right model. I don't think that it's a bad model in order to make sure that the tool that the clinicians are using, that EHR tool perhaps is solid and has all of the data that the caregivers need in order to trust what they're looking at, but it is an interesting element, as we create these standards, what is going to be that weigh station, if you will, as we disposition the data.

David Lansky – Pacific Business Group on Health – President & CEO

Anything else?

Hank Fanberg – Christus Health – Director of Technology Advocacy

Yes. A couple of quick comments: To me, one of the issues that it raises also is what's the value in the data, and who is using that data, and what value are they looking for out of the data. Historically, the electronic medical record was not designed to do what we're doing with it today. I think this committee has an opportunity to perhaps set some future definition for the electronic medical record.

The groundwork was laid in the IFR with the modular EMR, but being active in two different states, regional extension centers, the concept, I think, is a difficult one for them to grasp. So there may be an opportunity for this committee to make a recommendation that as EMRs develop in the future, that they expand to allow these capabilities or, at a minimum, that some modular component, which will allow you to capture the context of the patient.

Currently, I'm a Ph.D. student, and I was reminded of the discussion, quantitative, qualitative data. The EMRs do a great job with quantitative data, but it's that qualitative experience that it doesn't give you. So perhaps some further defining of what the electronic medical record could do and should do in the future, 2013, 2015, down the line, might be something this body might want to consider.

David Lansky – Pacific Business Group on Health – President & CEO

Thanks, all, very much. I think I have Paul first and then Neil and then Christine.

Paul Tang - Palo Alto Medical Foundation - Internist, VP & CMIO

I want to thank the panel as well for your remarks, for the prepared remarks and the answers to the questions. I think this panel and the panel before really do a fine job at being an add or maybe a counter-add to speaking for the urgent need to break the status quo of the paradigm that we live in and not to perpetuate it for sure.

As Carol was testifying, I thought about a comment that someone made when my dad had a stroke, and he said stroke happens to a family. And that just hit right home because, one, its impact is an entire family or community. But, two, there's this untapped workforce in the family and the community that could be leveraged. So I really liked, Carol, as you were describing how you use HIT ... in showing, in visualizing, in producing your video, and then in testing the understanding of the individual and presumably the people around that individual, so it really implemented your three E's: the engage, the educate, and the empower. It just seemed such a dramatic example of that.

The question, and to the rest of the panel as well is, first, how did you get to that place because you had to do that without incentives, not that you have any new incentives, but without any incentives. And so what is it with the policy levers that we have to explore, and particularly in meaningful use, what could we do to encourage or to incent the rest of the industry to get to the place that you did? James talked about the inefficient workarounds that have to be done with today's products and today's market that hasn't done anything different than to give you what you had to deal with. How can we move the whole marketplace to create something that you had access to, Carol?

Carol Raphael – Visiting Nurse Service System – CEO/President

I can start by saying, one of the things we've been spending, I would say, the last three to four years working on is putting together a quality infrastructure, and we actually started with our board, convincing them that part of their responsibilities entailed their trying to help us define and measure quality. And they were very resistant at first, but they came around, and now they really do hold our collective feet to the fire.

Then we had to start with and spent a good deal of time trying to define what we meant by quality. One of the more challenging areas was in the mental health field because we also do a lot of work in mental health. And once we did that, we have over 100 community health teams. Each of them has quality indicators, and on our outcomes Web site, we measure how they're doing in each of those areas.

Then, after three years of working with our union because our professionals are unionized, they agreed that we could tie bonus. There's no withhold. It's only bonus, but that we could tie bonuses to quality

results. That cascaded down to clinicians understanding that they could not attain the quality results without engaging, educating, and empowering the patients and their families. Therefore, their EHR became a shared tool.

It was no longer just their tool. It was something to be shared with the patients and their families. So they will go in and say let's look at your blood pressure. Here's the chart. This is where you were. Look how great you're doing. Only this much more to go, and there are two things you can do that are going to get you there. While they're thinking, if you get there, I'm going to get there. So I think that was just an integral part of our approach.

Patti Brennan – UW-Madison – Moehlman Bascom Professor

If I may, I want to comment that the patients are already doing "it". David mentioned some of the photographs we found ... households. Thanks to support from Eric, I was one of those Intel academic funded researchers.

People already have pretty sophisticated ways to keep track of this. We saw Rachel's binder. We see the lists on the refrigerator door that reminds people to do things. One of the incentives structures that I think we need to do is to build on what people are already doing and to rethink the incentive models from not necessarily being something that we are anticipating in the future, but rather, as ways to create the infrastructure to do more what people are already doing or do in ways that are done.

Now who would have ever thought that my son would have 2,200 songs on his iPod individually downloaded from iTunes at \$0.99 a piece? We need to think about what are people already doing that we can build on.

Paul Tang - Palo Alto Medical Foundation - Internist, VP & CMIO

James, just to bring it back to your example of the situation you faced, what could have made a difference? Is there any meaningful use criteria that could have made a difference in getting you the tools that you would rather have, either for your patients or your providers? What would it have taken?

James Ralston – Group Health – Associate Scientific Investigator

I think, in all honesty, we were starting these research projects at a time when this was so far off the vendor's radar, and part of that is because the research hadn't been done yet. And part of that is because there's no incentive for any of the industry to do it, except for the few organizations that have integrated care and delivery like ours, and so we're not concerned about reimbursement per visit. We're concerned about taking care of the whole patient, however best we make those connections.

But the EHR industry is not particularly interested in models of care that are innovative towards that. But I think now, as we look at it, if we had the ability to upload that data into a way we could share it meaningfully with patients online and providers could visualize it in their offices simultaneously, so when they're in the clinic office with the patient, they can look at it together. When they're online with the patient, they can look at it together. That would have made a big difference for us.

I think through a lot of Patti's work and some of the user centered design work earlier, we've figured out more efficient ways for patients to be able to get that information to providers, whether it's from a glucose meter, a blood pressure meter, or whether it's from an observation of daily living through a phone or some other device. So I really think now is a right time for them to be able to figure out how to integrate those into the EHRs, and we've done some good, user centered design about how to figure that out.

Speaking to your other question about how do you move towards educate and engage and empower, I think it gets back to this, what you measure, you kind of get. And the message, if you say patient experience is one of the measurements, it says patient experience is important. And that's a message that a lot of the provider community needs to hear. I think it's the first step to saying patients experience really matters, and that's really novel in the world of a lot of care. So it's not the same domains as engage, educate, and empower, but it's a really important first step.

David Lansky – Pacific Business Group on Health – President & CEO

Last comment and then Neil is up next.

Dave deBronkart – Society of Participatory Medicine – Cochair

We could bring to bear a lot of market force if it were easy for somebody to ditch a provider and go somewhere else if the customer experience sucks. I know that's non-trivial, but if it becomes practical for somebody to just say, look, give me my records, I'm leaving. And I mean like now or tomorrow or in a couple of days. If that can really happen, then some competition can set in, especially if consumers know they can do that. That's the education piece.

Neil Calman - Institute for Family Health - President & Cofounder

I also want to add my thanks to the panel. I think this has been fascinating. I guess what I would like to pose is this. We heard a lot about the need to sort of do this in a very patient centered, family centered way, collecting information from people. And one of the things I'm concerned about is if we sort of move forward, and we learn how to connect a blood pressure device and a scale and other things like that. I'm sort of thinking about what Patti said.

The information we need to collect is different for every single patient. So for some of my patients, what I want to know is how many times they were able to get up out of bed in a day. For somebody else, I want to know how many times they went to the bathroom. For somebody else, I want to know how many pillows they've slept on. We create parameters as we talk to people about ways of monitoring their own health.

And so I'm wondering if there are sort of generic or more general ways that we can think about capturing information that allows us to actually have a conversation with somebody, decide what parameters need to be followed, whether they are patient generated or not. This, to me, has a parallel to some of the discussions about how EHRs capture data, so I was visiting another practice where the patient history is basically recorded in checklists. Every single thing is in a checklist, and we completely rejected that in the process of our starting thinking that, in affect, it's in the richness of the patient experience. It's captured in dialog. It's captured in text.

And so one of the things I get concerned about is, as we sort of structure everything into little pigeon holes, is we want to capture it, but we want to capture it with all the richness of people's experience in what's going on, and that sort of defies the ability maybe to digitize it and count it. And yet, we also have to be flexible and figure out ways that we can give people tools to monitor the things that are important in their own care. So I'm seeking comment on whether or not you all have a vision for how that could be done, both broadly and in capturing all different types of data, but without sort of losing the richness of what people's experience is by sort of capturing it all in categories and numerical values.

Dave deBronkart – Society of Participatory Medicine – Cochair

Ten, fifteen years ago, I worked for a firm that wed the development of a standard in the print industry, and boy was that something trying to get a dozen vendors to agree on a standard vocabulary, and that

was for one special type of printing, never mind human health. The criterion by which we were judged was adoption, whether people were actually going to get there and get the job done.

I would urge the group, although there are some things that can be quantified and tracked numerically: blood pressure, lab results, and all of that. But if we want to get widespread adoption of data mobility, I'd urge the committee to accept just plain, free form text. Moving that text around is going to enable portability.

And the other thing is that sometimes there's a use for a standard where it accomplishes something concrete. It's not clear that everything, all the medical information, like all the things that you mentioned, that there is some universal standard for them. I'd say keep it simple.

Hank Fanberg – Christus Health – Director of Technology Advocacy

Not necessarily in counterpoint to Dave's comments, but if some of the information is not in a standardized format, those that need the data are not going to know what it means and what to do with it, so you need some type of interpretation going on. And what we've instituted at Christus right now, what's doing that is our community health worker. Think about the data that you're collecting. The data is going to be used for different purposes. Some of it may have a time, maybe time sensitive, so getting back to preventing readmissions to the hospital.

You don't want the data to be collected and go into a repository or into a PHR or someplace where it's going to sit and wherever the clinician or the care team gets together and says let's take a look, and download it and see what's going on with the patient. There's a time sensitive element to that that needs to be taken into account. So we need to understand what the data is going to be used for at that particular point in time, and the workload that is going to be required: Who do we want to have this data? Who is going to act upon it?

And right now, good, bad, or indifferent, what we're doing at Christus is using the community health worker as that interface because healthcare really is a team sport now. It's not just the individual practitioners. You really need the team. The team needs to involve the individual, but how much of the data, how much of the information is time critical. How much of it isn't? What do you want to do with it? There's no one exact purpose for all the data all of the time. As long as we take that into account, I think we can do some things with it, but that's kind of our workaround for the time being.

Carol Raphael – Visiting Nurse Service System – CEO/President

There was one other thing I wanted to add in line with that, which is, I think, Neil, you're talking about the tension between customizing and individualizing, and our move to standardize. I know at one of the New York eHealth Collaborative board meetings, I think, Neil, you might have been there, and I don't know, Dave, if you were with us yet. I don't know. Jim, you might have been there as well.

But one of the foundations in Upstate New York did a survey of consumers, and I was struck by one of the things that they pointed out, which is a number of them were very concerned about practitioners who only looked at the system and were completely driven by the structure of the system in terms of their interaction. And they really kind of made a plea for the practitioner putting the system aside and just interacting with them and listening to them, and just looking them in the eye because they said there was just this demise of eye contact that had occurred. So I think that is a real tension, and I don't know what the answer is, and it's just something that's invaluable, and we don't want to lose, as we move along this road of meaningful use of HIT.

David Lansky – Pacific Business Group on Health – President & CEO

Thanks. Patti, then ... Christine.

Patti Brennan – UW-Madison – Moehlman Bascom Professor

I'd like to separate your question a little bit, Neil, from the tools that are going to be available for a clinician to engage a patient in a specific period of time, whether it's a week, a month, or a year of watching how many pillows you use, how many steps you're taking every day, and the sort of underlying data we need to know about people in our lifelong record that might actually be built over lots of periods of time. Then at a third, if you will, sub-layer onto that with the infrastructure that's needed to capture and control and manage data.

At the front end, we have an emerging group of health professionals and patients, frankly, who know how to download ring tones, and they're able to get their airline tickets online, unless they're in Europe, and we have an environment where people are engaging more in an information flow. So we need to rethink how we're using information and information tools in the clinical practice setting. We need to be able to give clinicians. This was mentioned ... give clinicians tools that they can rapidly mobilize with patients that give them the flexibility to do an e-visit instead of doing a face-to-face visit or a bunch of e-visits to get ... so they can monitor more closely. You have to think about the three-legged stool of care practice as being professionals, patients, and technologies.

In terms of the infrastructure, we do need to keep a piece of ever-ready information flowing. It is important to know where I was born and that I had surgery when I was 21, but it's not needed to be mindful every day. So thinking about this other lifelong record, where does it reside, how do we get at it, what kind of distributed tools do we need to me is a non-trivial challenge. We've thought about making great big buckets and shoving it in. That's not going to work, but thinking about information integration tools may help.

David Lansky – Pacific Business Group on Health – President & CEO

James?

James Ralston – Group Health – Associate Scientific Investigator

One final comment: I think you were speaking about the tension between structured data and narrative, and is patient entered data a part of both of those? And it definitely is. We have very rich patient entered narrative data in our secure messages that are shared between patients and docs, and the docs, when you reply to a patient message, you enter a narrative, and it's a richer narrative, arguably, than much of what we see in our visit notes. And, on the other side, the patients enter that narrative back to us. And I would hope that as we increase the transparency of other notes encounters to patients that some of the structure checklists that you lament may change and shift, hopefully back more towards a narrative engagement with the patient through a shared document.

David Lansky – Pacific Business Group on Health – President & CEO

Thanks. I think Christine was our next questioner.

Christine Bechtel - National Partnership for Women & Families – VP

Thank you. Thank you very much for your time today and all the expertise that you're bringing. I actually have two questions. The first is around data. I heard Regina talk about kingdoms of data and the fear that we're sort of creating unencroachable kingdoms of data. I heard Dave, you talk about the patient as the platform for integration.

When I think about those comments, and I think about the meaningful use criteria that were in the proposed rule, as I think about the criteria that were in the proposed rule, and I think about the experience

of someone who is getting access to their health information through their primary care provider, getting access to their health information through a specialist, getting an after visit summary from that specialist, and then getting discharge instructions electronically from the hospital, all of which could be in very tethered and proprietary systems. I start to worry that what we're really doing is we're unlocking the data kind of. But really, in the end, there's no god way for patients to pull it all together, or providers even to sort of pull it together. When I hear Carol talk about the importance of a continuous healing relationship, we have to have data that supports that spectrum and not just the sort of provider based, setting base, typical healthcare model.

My question to the panel is, how do we make sure that we don't run that risk? And how do we do that in a way that is, of course, private and secure and, at the same time, respectful of the needs that the patient has for information? Do we create some kind of a download function? How do we handle that?

Dave deBronkart – Society of Participatory Medicine – Cochair

Innovators, essentially, let innovators get at it and solve the problem. Sure, there are privacy concerns need to be dealt with, but my key concern is, let's not let that prevent us from getting started on trying to solve the problem. When I think about my own family, my father's final illness and my sister was in Annapolis was sort of an orchestrator of care. She's no physician, but she's a physical therapist, but just pulling the information together. I mean, they organized it all. She and my mom organized it all on paper, right?

And so if we can pull it together that way, we can certainly do it if it's electronic. And in particular then, if we start to have Web sites that can get their hands on it, and like become the equivalent of trip advisor where you've got your profile and preferences and everything, mint.com, and so on. I'm not at all concerned about the fact that that needs to be solved. I'm much more concerned about we won't have a chance of solving it if the data is locked up.

Christine Bechtel - National Partnership for Women & Families – VP

I agree, so let me clarify my question. What I'm worried about, and maybe you'll tell me that I'm wrong, and I don't understand the technology, which is possible. If I have a portal view into my physician practice, I don't think I can unlock that data. I think I can see the data. I can print the screen off. But I don't think I can actually port it out of there so that a Web site or, you know, a platform can use it.

Dave deBronkart – Society of Participatory Medicine – Cochair

I tried that. Yes. Sure.

Christine Bechtel - National Partnership for Women & Families – VP

So I guess my question is, is that a risk? How do we address it if it is?

Dave deBronkart – Society of Participatory Medicine – Cochair

You mean just the fact that today they won't let me do that?

Christine Bechtel - National Partnership for Women & Families – VP

In the first payment year of meaningful use, I'm starting to get a little bit. I think we've made a good start in a lot of ways, but I'm starting to get nervous too that what the unintended consequence of the criteria in the proposed rule anyway is in part that we actually won't be able to move data around, so definitely a good start. But I'm just wondering if my concern is founded or not.

Dave deBronkart – Society of Participatory Medicine – Cochair

You're saying there's a requirement that the data be exportable, but the--?

Christine Bechtel - National Partnership for Women & Families – VP

Right, there's not a requirement that be exportable. Yes.

James Ralston – Group Health – Associate Scientific Investigator

Isn't there? I mean you have to.

Christine Bechtel - National Partnership for Women & Families – VP

Well, not in any kind of – we don't.

Carol Raphael – Visiting Nurse Service System – CEO/President

It doesn't have to be computable.

Christine Bechtel - National Partnership for Women & Families – VP

Right. It doesn't have to be computable. You can access it in a PDF, or you can get it on a USB, or you can get it through a portal. But I'm not sure, and tell me if I'm wrong, that there's anything that says that you then can actually move that data around outside of the system or the mechanism through which you're taking a look at that data.

Dave deBronkart – Society of Participatory Medicine – Cochair

When you say move it, you mean like if I take this PDF. I can't.

Christine Bechtel - National Partnership for Women & Families – VP

Yes, you can move it, but it's not computable.

Dave deBronkart – Society of Participatory Medicine – Cochair

I can import the data into another system.

Christine Bechtel - National Partnership for Women & Families – VP

I don't know. From a PDF, can you?

Dave deBronkart – Society of Participatory Medicine – Cochair

Absolutely. Sure. You can extract the text from a PDF. I mean, it's this simple. You can go into a PDF right now and put the text cursor in there. Do control A to select all, and paste it into Word. Now it may have some messing formatting to it, but you let somebody like Adam Bosworth at Keas get his hands on that stuff, and that will be solved quick, especially if there's money to be made at his end making it happen.

Patti Brennan – UW-Madison – Moehlman Bascom Professor

I'm going to ask you to pull forward the 2011 statement of electronic access to data into the next two phases and get increasingly sophisticated about it because electronic copy, be that as it may, may still not be actionable. The numbers might be there, but they might not. There are technological solutions that are moving. Mint.com actually can screen scrape and get some context interpretation of your data, so there are some solutions happening outside of health IT. But the efficiencies and the ability to do workarounds is only going to happen if we can export data in a computable form, which has a lot to do with not just the number, but what does the number mean and what is the standard related to it.

...I'm going to ask for the committee to guide standards where they absolutely need to be and not where they shouldn't be. Right now, standards are too far in the front end of the data process and not far enough in the backend, so we've got standard screens, and we've got terminologies, but the backend

operation is still, from the patient's perspective, the visibility of the data may be less important than the ability to make a chart or a plot or an observation of it. The need for your group is, I think, to realize that we're not done exporting patient data in 2011. There's got to be criteria every ... what that means, and that it needs to be capitalizing on solutions that are coming from other sectors, not just healthcare.

James Ralston – Group Health – Associate Scientific Investigator

And just one other thing, I'll agree with your observation. We are creating and we're cognizant of, through the REC program, we're creating many, many, many more points of data with all these primary care docs that are going to be coming up with their own EHR systems. Now again, that's another round of data....

When you start to look at stage three collaborative care, how is all this data going to integrate and what are we going to do at that integration level, and where is the aggregation level that's necessary in order to deliver those collaborative care models? It's an interesting problem. I think we've got to get a handle on it such that we can get the vendor community, the standards community, everybody steered in the right direction so we hit it in the right year. But we might be late, so it's a good time to talk about it.

Christine Bechtel - National Partnership for Women & Families – VP

So I think we need a pathway on that and would welcome input on that offline. Here's my second question. Patient experience, Jim, you talked about patient experience, and I'm thrilled that you did. Folks have heard me say it for quite some time that this has to be meaningful to patients. And if we don't ask them, we don't know. And I think there is a strong body of research that tells us that a lot of the experiential factors, which, Carol, you talked about the triangle, and the experiential factors are often sort of the lower part of the sort of sideways part of the triangle, and they don't get as much weight as some of the clinical quality side. But when you ask patients what really impacts their ability to improve their outcomes, it's experiential stuff.

Jim, my question to you is, having piloted, I assume it was the HIT CAPS module, was it helpful to you? Did you learn anything? And is it an instrument that we should look at for future years or is more innovation needed? Can the instrument keep pace with technology? And I'm asking because, when I read through the module, I think there was a lot of – you could almost use it as a way to assess adoption levels of certain technologies. But the presence of absence of technology is not necessarily meaningful to patients.

So I'm interested in a lot more of their experience with how messaging or other technologies help them improve health outcomes or not. And I'm not sure that the survey gets at that side of things as much as it does, does your doctor give you the ability to do refills online or message, etc. I'm just curious if you could talk about anything that you guys have learned from the module.

James Ralston – Group Health – Associate Scientific Investigator

Well, we just completed that survey last week, and so I don't have specific information yet on that data, and I know the CAPS folks have got two other sites involved, so they'll be pulling that data together. When I looked at the questions, I didn't think that they were as mature as they could potentially be, but I did think that they echoed some of the experience of other access to care well, so for instance with messaging, it asked, did you get a timely response to your question, and did your provider answer your question sufficiently. Those are pretty good starts, I think, to asking if this service met your needs.

I think there's real opportunity to build out some of those experience questions, but so far I think that the idea that they say we want to look at online engagement in the context of broader access to care, including questions about telephone access. Did you call this provider? Did you get timely access? And did you see this doctor in person? And did you get timely access?

When you look at all of that in the context, I think it's the right approach because if you provide really good online access because you measured that, but didn't measure anything else, then you may be shooting yourself in the foot because you'll get people who would be doing online access rather than calling on the phone because they can't get through. So I think the overall approach that I'm not endorsing CAPS, but I think the idea of them looking at the overall approach to access and service and patient experience is the right approach. And I think, in the next year, we'll have more answers to the questions of whether that specific instrument is useful or not.

Christine Bechtel - National Partnership for Women & Families – VP

Thank you.

David Lansky – Pacific Business Group on Health – President & CEO

Charlene?

Charlene Underwood - Siemens Medical - Director, Gov. & Industry Affairs

...for your input on this topic. I actually wanted to drill down a little bit, and I think it links back to our meaningful use criteria, and maybe focus it at Carol and Hank. Carol, you had mentioned and this is around one of the measures that was in our meaningful use our outcomes that we'd been looking at with readmission rates. And you'd mentioned specifically you were able to decrease readmission rates through the services.

What I wanted to do was to better understand are there data barriers, or the things that could support you in the transitions of care or are there other barriers that are keeping you from reducing that more, or do you have plans to reduce it more through getting more access? I just wanted you to look at that little slice. Then maybe from the hospital side or even the ambulatory side in terms of a view in terms of how to help with the data liquidity in this particular space. Is it transferring care plans? You know kind of where I'm going. Thank you, Carol.

Carol Raphael – Visiting Nurse Service System – CEO/President

Certainly one of the things that we have done is to develop an algorithm, which can predict the risk of rehospitalization, and that has helped us enormously to target our interventions. And then, for those who are at high risk, based on our algorithm, which has been remarkably valid up to now, we frontload visits. We absolutely have to get a follow up appointment because that has been a major barrier that someone is told, come to see me in four weeks, and then they call, and then it's six weeks that they get an appointment. We really become the intermediary that is hounding the physician to get a follow up appointment within the first week. We have found that to be critical.

And then we have an emergency plan, which is, if something goes wrong, you spike a fever, you have a rash, you panic. Call us in the middle of the night. Don't go to the ER.

What is really a barrier that I think kind of intersects with what we're discussing is there isn't that record, this continuous discharge record that is passed onto us. So often we're starting de novo with all of the information, which you often wish was passed on to you in an easily accessible form. So I think that if we could get that early, and we could act on it, I think it would really help in the readmissions area.

Then the other thing that I think would be helpful is in regard to the emergency department, if there was much better communication with the emergency department than there is right now. That's another barrier that I see.

Hank Fanberg – Christus Health – Director of Technology Advocacy

One of the other initiatives that we've undertaken within the hospital setting and trying to relate it back to meaningful use, I think it may actually wind up touching on computerized order entry. As you had mentioned, the care transition areas are areas where you have the highest risk of something happening, someone having to be readmitted back into the hospital. So we have an initiative.

It's not very far along just yet where, when creating that initial order set, when the patient is admitted, to have that order set automatically transfer into their discharge instructions and follow up. Automatically notify the primary care physician or whomever the other physicians are, and translating that inpatient order set into an outpatient set of orders, if you want to call that a discharge summary, instructions, whatever. I guess you could call it that. But to keep the entire care team informed of what happened, number one, in the hospital and, number two, now that you're transferring from one location to another, actions that need to be continued.

The other thing that we do, we don't do this 100% just yet, but with those patients that we have identified that are of high risk, we send them home with a home monitoring device where we are collecting the physiological data automatically being sent to actually the call center that's actually manned by nurses. And this, in part, gets into also how some of the vendors have created their products and how they'll integrate into each other. That's a whole other story.

But the nurses are kind of the first line. They're taking a look at the information that's coming from these physiological monitors in the home. And they're the ones that are actually sort of manually integrating it into the current electronic medical record. So those are what we're doing. I'm just trying to say, how do we leverage meaningful use to help further that, I don't know that I have an answer for that just yet.

David Lansky – Pacific Business Group on Health – President & CEO

Thanks. I think James has a point, and I have one more question to wrap up.

Jim Figge – NY State DoH – Medical Director

I wanted to focus for a minute on the incorporation of patient generated data into the EHR, and I'd like the panel to help us come up with some criteria for prioritization. There are obviously many different data types that patients can generate that we could wrap around and meaningful use criteria and ask those to be incorporated into an EHR. But my question is, how do we decide what actually adds value to the patient's experience as they interact with the healthcare team?

What types of data will be used by the healthcare team to actually improve patient outcomes, to improve quality of care delivery, to improve care coordination? To get to that, I'm thinking that we need to have an evidence base, so I do want to congratulate Dr. Ralston for the work that his team has done in looking at certain data types like home measurement of blood pressure. My question is, should we primarily focus on data types that are already supported by evidence indicating that the collection of that data actually improves patient outcomes? How should we analyze that evidence? Should we partner with the federal agency for healthcare research and quality, which does comparative effectiveness research, so should we propose that ONC team up with AHRQ and review the data and inform us? What data is high quality data? What data will actually improve patient outcomes? How do we approach this, and how do we prioritize it? Maybe I'll start with asking Dr. Ralston to comment.

James Ralston – Group Health – Associate Scientific Investigator

That is a loaded question. And I'm sitting next to Patti Brennan, who I know spends a lot of time thinking about this too. Well, you actually asked a couple different questions. You asked what's going to be meaningful for providers from the provider perspective in terms of health outcomes, and then you also

asked what would patients want, and those two things are often not the same. I think it's a good idea to recommend that AHRQ partner with ONC on establishing those.

We have targeted hypertension and folks with diabetes as common chronic conditions that are data heavy and that are cumbersome often for patients and providers to collaborate online because of just the exchange of data can be a challenge, particularly with diabetes with all the blood glucose measurements. I am not sure that's what patients would say would be their priority. They may say it's more important that my doctor know specific things about my living situation, about whom my caregivers are, what name I want to be called, what's for some patients their spiritual connections. It's not clear to me that I really know what those priorities are.

I can say that we are developing an evidence base for those other measures around blood pressure and diabetes care. It's going to be tricky because I don't think we're probably going to be able to have randomized trials that really honor all those patients preferences, and I think we're going to have to look to groups like Patti's Project Health Design group to really help us inform some of those preferences, so teaming up with our core other agencies, I think, makes sense.

Patti Brennan – UW-Madison – Moehlman Bascom Professor

I have to weigh in on this one also. It depends on why we want to use an EHR and why we want any data in it. So the answer to your question lies in what is the purpose of the EHR serves in practice. I'm not a physician, and I'm not involved in direct clinical care nursing, so I really don't know why people use extracting from an EHR. I know why they put things in. They give it a test. They make an order. They record a medication.

So we need to look at what's the output function, and it seems to me that we need to make sure it's not always human readable, that is that there's good reason to have data like blood pressure data feeding constantly into an EHR that would set off an alert as opposed to data that will feed ... EHR, and somebody has to physically look at. I think we need to think about the EHR as a platform for action, not as a book that we read.

I'd like us to think about – I'd like us to broaden the types of information tools we use in healthcare. Right now, everything is focused on the EHR, and I understand that that's where we're tightly focused is the meaningful use criteria of electronic health record. But if we could begin to think about, there might be reasons why, for a particular period of time, say a pregnancy, we need a different set of information that's actually more ... that helps us guide a woman through a pregnancy process or helps prepare the family for a new child and may not have to be the actuarial record of the number of times she was weighed and had a protein urine test, etc. for her prenatal care. So we need to think about a richer set of information tools.

But specifically, how do we prioritize for consumer-generated data to put into an EHR? I would say we have to go after our major public health threats first: diabetes, cardiovascular disease, hypertension, data intensive diseases where we know clinical management and patient engagement are essential to survival.

David Lansky – Pacific Business Group on Health – President & CEO

I think our time has come to an end. This has been a fantastic and fascinating panel, and I've got a lot more questions and about 30 to-dos that I've noted, so thank you all for making the time to come and help us start the conversation about this. I'm sure we'll be talking to you some more as we start crafting our approaches to meaningful use. Thanks very much.

Patti Brennan – UW-Madison – Moehlman Bascom Professor

Thank you.

Paul Tang - Palo Alto Medical Foundation - Internist, VP & CMIO

Thanks to the panel, and thanks to David. We'll adjourn for lunch and reconvene at 1:15.

Judy Sparrow – Office of the National Coordinator – Executive Director

Good afternoon, everybody. I think we're ready to reconvene the meeting, and if the operator could please open up the public line and let me know when that happens. Thank you.

Operator

You are bridged. The public is connected.

Judy Sparrow – Office of the National Coordinator – Executive Director

Okay, everybody. Please take your seats, and I'll turn it over to Dr. Tang.

Paul Tang - Palo Alto Medical Foundation - Internist, VP & CMIO

Welcome, everyone, back to the meeting. We had a wonderful morning with a couple of very stimulating panels having to do with the use of electronic health information in the real lives and the use of incorporating patient generated data into the whole health and healthcare process.

In this final panel for the day, we're talking about some of the policy challenges and implications in terms of incorporating and meaningfully using data that comes from patients and consumers themselves. For this panel, Deven McGraw will moderate. Thanks.

Deven McGraw - Center for Democracy & Technology – Director

Great. Thank you very much. We've got maybe a little bit more flexibility on this panel because we don't have quite so many panelists as in the previous panel, but I'm still going to do my best to try to keep you within the five-minute timeframe because I think your testimony is obviously very valuable, but I'm finding that much of the information that we're getting from you is made more rich by the question period, and we want to make sure we have plenty of time for those.

I'll start with a very brief introduction. We have your bios in our packets. Similarly, we have your written testimony as well. I'll go ahead and introduce you all briefly, and then we'll just get started and go right in the same order we've been proceeding with today.

Our first panelist is Joy Pritts, who is the chief privacy officer of the Office of the National Coordinator for Health IT. This is a new job for Joy, but for those of us who know her, we know well her long expertise in healthcare privacy issues. Before she was at ONC, she was on the faculty of Georgetown University with joint appointments at the O'Neil institute for National and Global Health Law, and at the Georgetown University Health Policy Institute.

Next to her, we have Dr. James Weinstein. He's the director of Dartmouth Institute for Health Policy and Clinical Practice. He's a professor and chair of orthopedics at the Dartmouth Medical School and Dartmouth Hitchcock Medical Center, and professor of community and family medicine. He founded the spine center at the Dartmouth Hitchcock Medical Center, as well as the first in the nation's center for shared decision-making, both of which are internationally renowned. I'm going to skip to later in the bio because I really like this sentence. As both researcher and physician, Weinstein has been a strong advocate for decision-making partnerships between physicians and patients, particularly in cases where the choice of one treatment over another can be termed a close call. I liked that sentence.

Next to him is Carl Dvorak, who is executive vice president of the Verona, Wisconsin, based Epic. I didn't know that Epic was in Verona, Wisconsin. Now I do. Carl is responsible for Epic's research and development areas, as well as many executive and strategic activities of the company. And he's been with Epic since 1987.

Cris Ross is the executive vice president with CVS MinuteClinic where he has responsibility for IT and product development. Before that, he was CIO for United Behavioral Health, which is a subsidiary of the United Health Group. He has 26 years of experience in IT, healthcare and government, and is a member of our health IT standards committee.

Thank you all very much for agreeing to be with us and to testify today, and we'll start with Joy.

Joy Pritts – ONC – Chief Privacy Officer

Good afternoon, and I thank you all for having me here to talk to you today about policy challenges with respect to patients and their access to their health information. In my prior life before ONC, as Deven was mentioning, I did a lot of work in this area, in particular, researching on patients' rights to access their own medical records.

I think that, as a policy matter, that on a very grand scope, we all want to see that health information is made available to the patient in a timely fashion, in a usable form, and in a medium such that they can use, such as paper or electronic, and in a format or a health literacy level that's appropriate for the patient. When you use that as your end goal, you'll see that a lot of the policy that's in place now might not necessarily get you to that ultimate goal that we'd all like to see.

ARRA went part of the way to moving in that direction by clarifying that patients do have a right to an electronic copy of their information when it is held in that, when the provider maintains the information in an electronic health record. There is some confusion about just how extensive that right is under ARRA, and which providers it applies to. But I would say that it's important to realize that ARRA is a clarification. There is an existing privacy rule that's been on the books for quite a while that gives patients the right to access their information in the format in which they request if it's readily available. To the extent that there have been questions raised about the limitations of "an electronic health record" and what that might provide access to, some of those issues can be answered just by turning back to the original privacy rule and reading it broadly, as it was originally intended.

ARRA also clarified that with respect to medical records, well, electronic health information, that the only cost available for providing that information to the patient was the cost of the labor of responding to the request. It's interesting that that was spelled out so clearly in ARRA, but part of the reason that was spelled out was there were some states that were beginning to move slightly in an electronic fashion, and they had the inclination to include, amortize the cost of the record, cost of the system in the cost of the record for the patient. So that movement, I think, has been curtailed, shall we say, by the federal role.

One of the policy challenges in providing patients access to their health information, particularly electronically, is what information. What is the scope of the information they're going to be able to get access to? HIPAA defines that as the patient has the right of access to any information that the provider uses to make healthcare determinations about them. There is state law in interpretation that excludes information that is in a provider's record that has come from another source. That is a fairly common issue and a common interpretation, and so I believe that it will need to be clarified further going forward.

Also, what is the period of time that these records will be available to the individual when we're looking at an individual being able to create a longitudinal record? You need to look at how long health information has to be retained by a healthcare provider. This varies greatly from state-to-state with some states having medical record retention periods as short as five years. Those are on the opposite end of the continuum and require the provider to keep the information essentially forever. HIPAA does not address this issue. This is a state law issue as to the record retention rights, and it's traditionally tied to a tort law, so there are some potential unintended consequences of tinkering in this area if it's not done carefully.

State laws in general are paper based. Many of them are superseded by HIPAA, but they remain on the books, and this generates a significant amount of confusion at the state level due to inadequate training of physicians and of their staff and of just general information to the group as a whole.

And there is one area in particular, which has kind of risen to the top as being particularly problematic for a lot of people who are implementing electronic health records, and that is providing access to the records of minors. And generally, as a general rule, a parent has a right of access to the health record of their child. Where things start getting very sticky very quickly is when the minor has lawfully consented to treatment on their own, and then it is a very complicated analysis and difficult to determine who necessarily has the right of access or when the provider may disclose that information to the parent in general.

There are some healthcare systems that have addressed this in particular, and so they may be looked to as potential as models for addressing this type of issue. And with that, I will close my comments, having highlighted just a few of the policy issues that I'm sure that you all face as we go forward.

Deven McGraw - Center for Democracy & Technology – Director

Thank you very, very much, Joy. Dr. Weinstein?

James Weinstein – Dartmouth-Hitchcock Clinic – President

Thank you for the introduction and the opportunity to be here today. It's indeed exciting to see the representation and importance of the patient's voice in the transformation of the U.S. healthcare system. I've been a practicing spine surgeon for 27 years, first in Iowa and now at Dartmouth. Patient care is an important touchstone for me in my new role as health system president and as director of the Dartmouth Institute, home of the Dartmouth Atlas and the Microsystems.

A few years ago, Sheila was referred to me, and with her permission, I share her story. She came seeking a surgical opinion. She was told to limit her activity, given narcotic pain medications, and back surgery was her best option. On the exam room door was Sheila's one page, self-reported summary. Sheila, like most all of our patients, completed a computerized questionnaire prior to seeing me. Before she arrived in the clinic room, it was summarized real time and on the door waiting for me.

Like so many cases, this form provided me with nearly everything I needed. I knew before even meeting Sheila the problem had become much more complicated. This nearly 70-year-old female had SF36 scores suggesting depression. Her physical function was below age and sex match controls. She was on narcotics, inactive, and clearly having more troubles from the medications than her spine. The proper prescription for Sheila was not back surgery.

All this information was on this 8.5x11 sheet of paper completed by Sheila. This, and her clinical data, allowed me to have a patient centered discussion focused on her needs and expectations. Within four months, Sheila returned to her former self without surgery.

This patient's self-reported intake form is more important to me today as a physician than any MRI scan or test. In fact, today it is hard for me to imagine practicing without it. It would be like flying an airplane without instruments. I could see the beautiful scenery, but wouldn't exactly know where I was going.

When we speak about vendor interactions with patients in a meaningful way, we need to include discrete, patient-reported data. It needs to allow proactive outreach to complex, high-risk patients. It needs to facilitate home-based monitoring for care. Patient's records need to be easily accessible with just in time access with portability through standard data exchanges. One can't imagine having to call one's bank for access to their accounts. Why should patients?

Like cell phones, we need EHR apps available and compatible everywhere. In our practice, we go beyond core data, red flags and processes to facilitate personalized care plans with decision support built into real clinical practice utilizing shared decision making and online, computer-based decision tools based on the best clinical evidence from real world clinical practice. At the same time, we've done large, clinical comparative effectiveness trials as part of clinical practice, not as one off activities interfering with practice.

For the past 11 years, we have led an 11-state NIH sponsored study called SPORT. Now Web based, three concurrent cohorts are followed across the U.S. creating an invaluable resource for study and implementation of evidence-based care and measurement, including cost effectiveness.

For patients and their care teams, these EHR tools enhance our ability to be true partners with our patients in making informed choices about diagnostic and therapeutic procedures. By triggering automatic referrals to social workers, mental health professionals and, in Sheila's case, drug counselors, patients receive team care that is more comprehensive and often more valuable than what they would receive from a physician alone.

In our system, aggregated patient self reported data is available on our Web site. Patients can view our outcomes and clinical results, visit our shared decision making center, and have their values and preferences be part of the clinical decision-making. This kind of transparency and patient involvement is essential to gaining patient trust and confidence and in improving the delivery of healthcare. We use real time data from our patients for our patients, building on the institute of medicine work. NQF states that the evaluation of patient care over time is essential. Patient perception is most important. Care must meet the needs and goals of the patient and their family.

Today, we have the opportunity to put real measurement behind the words value-based care, reduce waste, increase safety, and produce better outcomes. Thank you.

Deven McGraw - Center for Democracy & Technology – Director

Thank you very much. Carl?

Carl Dvorak – Epic Systems – EVP

Thank you, Deven. I'm Carl Dvorak, and I think I'm going to abandon the formal testimony and go to something that I can add maybe some additional value today. Neil, it's harder to go last than first.

I'm a computer scientist, so I'm the person at the intersection of hopes and dreams and bits and bytes. I live in the world of the specific, what you can write code about, what you can actually accomplish with computers. And I thought one thing we could share today is what we have found to actually be practical and be reasonable for people to do and give you some experience in terms of how our sites have employed those things.

About 12 years ago, maybe even a little bit longer now, we came up with something called myChart, and the carbon dating of the Internet world, you can go back and look to see who originally registered the myChart domain name. It's an interesting application that allows patients to connect directly with their providers. We also have since introduced the ability for patients to download their documents away from their provider into a non-tethered PHR. We call it LUCI, but it allows patients to take their data with them and to go away from any particular provider.

We also have introduced the ability for patients to use a USB download and to encrypt that download in such a way that everything is encrypted, everything except the meds and allergies, or nothing, to their preference. Those tools are interesting. We've also come up with an iPhone application for patients to use.

What we have found the most interesting is that patients actually are interested in their data, but what they tend to be more interested in is the communication back with their provider. It's the connection to the provider that seems to make the difference, not simply the data. I was commenting to Paul at break that it would be fun to reconvene this session after the interoperability crisis is resolved. I think much of what we experienced today in the conversation is not really about patient engagement. It's about making up the deficit of the lack of interoperability from provider-to-provider.

The patient engagement opportunities are huge, as we look at what Dartmouth has done, as we look at what some of the sites that work with our applications like Group Health and Kaiser do. It's amazing to see how an activated patient can really fundamentally make the difference in outcomes. I think it is maybe one of the most significant opportunities for us in the future. We've tried lots of different things, lots of penalties, lots of stimulus, lots of reporting, but it seems like patient engagement really might be the thing that moves the needle the next biggest chunk.

I think we do have the largest PHR out there, and many of our sites not that are, I won't say aggressively, but maybe assertively pushing it, can achieve 30%, 40%, 50%. I think Jim commented on 59% adoption across the membership base with a fair number of proxy accesses being given out. I think any individual site might give out between 5% and 10% proxies, obviously children's hospitals are higher, where you might allow a family member to have access to your chart remotely to take care of you.

The next horizon that we're working with many of our sites on is the notion of patient engagement through patient entered data into the EHR. It turns out to be a little bit tricky because it's not actually the same data as the clinician's data. The clinician works in the very concrete world of white blood cell counts and CBCs and heights and weights. And patients tend to work a little bit more on the symptomatic impression data, so trying to connect those two turns out not to be trivial, but it is one of the newer areas that we've been focused on for the last few years and have the ability for patients to do things like the SF36, and for providers to see that data.

And, as well, it turns out that it's actually quite practical to take machine generated device data from the home. We use a couple tools, but it's lacking our standards. So to get a home glucose, to get a weight, to get a blood pressure, it's very doable, but it would be a lot more doable if we had standards. It would become economical if we had standards. Today it's doable, but standardization of the flow of that data would make it economical and in reach for everyone.

Some of the specific questions you asked about the data export, we don't see a lot of patients opting to export their data yet. Maybe they will some day when there are more things they could do with it. From a privacy perspective, I think, we benefit from the fact that the patient knows the custodian of their

information is still their health system, so they know it lives and breathes by the rules and regulations that affect the health system. I do hear both patients express concern about that data once it flows out of the health system, uncertain what'll happen with it. I think there's a lot of concern, both from the patient perspective that their private information used for advertising, you get a general sense of concern from that.

From the provider side, we see a larger sense of concern because I think they're fearful they'll have to dispel the myths of advertising every time those patients come back, so there's even a bit more concern on the provider side. I think understanding that a patient will be mostly motivated to fear or to comfort based on what policies we create with regard to the suitable uses of their data. If they knew that their data could not be used inappropriately, they would probably much more likely to let it free flow out into other tools and applications that might thrive on top of open standards.

I do think, as Paul commented earlier, there's definitely an elephant in the room. The elephant, as far as I can see it, is that most providers that we come in contact with aren't the sort of providers that benefit from the model of a Group Health Cooperative or a model of a Kaiser. They're fundamentally enslaved by the level of service calculation. And try as you might, it's hard to break through that unless you just want to go into charitable good works. And I think there's a problem that if we don't face the issue of compensating providers for a new kind of medicine, we really won't fundamentally change the game more than a couple percentage points, and I'll stop with that.

Deven McGraw - Center for Democracy & Technology – Director

Thank you. Cris?

Cris Ross – MinuteClinic – CIO

Thank you. I'm going to talk a little bit about our experience at MinuteClinic that might be useful to the group, and then I'm going to try and answer some of the specific questions that you asked. MinuteClinic, in case you're not familiar with who we are, we provide basic medical care in 500 clinics in 25 states conveniently located in CVS Pharmacies. We're joint commission accredited. We're about to treat our six millionth patient, and we routinely get 90+% consumer satisfaction scores, and we spend a lot of time on consumerism in healthcare.

The kinds of things that we do that make that happen, there's really two design foundations around what happens in a patient visit and how it's supported by electronic health technology. The first is to make sure that the visit is evidence-based, safe, and efficient. The second is to make it suitable for the consumer in how they consume the healthcare at the time they're in our clinic, and then how are they going to use that information to receive treatment elsewhere as they integrate what they do with us in other care systems.

We do a couple of things. First, every patient visit starts with a medical history that includes medication history and medication reconciliation with patient consent we get data electronically. Second, we put all the data into an electronic health record system that includes decision support to make sure that we stay on track with the evidence-based care that the patient needs to receive.

Third, we always provide the patient with a printed copy of their visit at the end of the visit. That includes things that are specific around their visit, as well as patient education sheets around their diagnosis. Fourth, we provide a copy, an identical copy of that record to the patient's physician. We ask them who their PCP is and we communicate it within 24 hours to their physician.

Fifth, we provide the patient with electronic access to their records. They can download their record either in CCR or PDF format. They can also link their record with Google Health or Microsoft HealthVault. We also try to make it easy for them to establish a Google Health or Microsoft HealthVault account if they don't already have one.

You asked what's required for vendors to be able to export data and what's the role of providers in making data available. I want to really answer those together because our experience is that medical practice and technology need to be complementary. The first thing I guess I'd say is that vendors and providers need to make dedicated efforts to structure data so that it's both human and machine readable and also physician and patient usable. All four quadrants of that sort of diagram make sense.

And I think I was thinking a lot today hearing the testimony around the work that we're doing on the health IT standards committee in which there's been a fair amount of tension between what's been characterized as the informaticist [sic] camp and the Internet camp. Supporting established models that work and trying to find new models that'll innovate. And some of the conclusions that we've reached is that the perfect solution for some of the big guys are not necessarily perfect solutions for the small guys or for innovation, and I'm even more convinced, after hearing some of the testimony today, that the kind of solutions that are appropriate for a small ambulatory office are probably likely to be suitable or maybe even most appropriate for the kinds of things that consumers might want to get access to their data as quickly as possible.

You also asked about privacy and trust issues that might keep this sharing of data from happening. And I don't really want to talk about what the barriers are. Instead, I'd really like to talk about how we can build trust in order to gain consumer engagement and support.

A couple of things: First, other industries show us that providers and consumers are willing to accept more expansive use of data if there's benefit to them and if they see certain uses becoming commonplace. Ten years ago, sending an e-mail to your mom or buying something online with a credit card was a pretty pioneering event. We've come a long way in the last ten years. But in a lot of ways, we haven't changed our mindset to embrace that. I think there's a large degree to which we've made privacy an excuse not to share data.

Second, consumer empowerment should be supported and empowered as much as possible, but we shouldn't require that consumers be responsible for assembling their own networks in order to move data. I'm troubled by the idea that we're going to have these underground networks of data where consumers have to fight against the system to get data from one place to another. It should be the consumer's right, but not their responsibility to move data from provider-to-provider for different uses.

Third, Health IT Standards Committee, in a recent hearing in the implementation workgroup, we had members on a vendor panel who said that they believed that the IFR and the NPRM standards obligated them to generate data for another provider, but not necessarily obligate them to use data from another provider. And that was chilling to some of the folks who were participating in that panel. And I would urge both the policy and standards committee to address that issue. If we don't make it required that providers and vendors consumer data, it isn't going to happen.

Fourth, I'd like to point to some concrete recommendations for consumerism that have come out of the Markle Foundation Consumer Engagement Group. I know that several people here are engaged in the Markle Foundation. I think they're really apropos. One is to allow low burden means to achieve stage one patient engagement, so we should shift paradigms so that the information is not provided only upon request, but is delivered routinely at the time of service. That's been MinuteClinic's model and it's worked

well. And by requiring that we make data computable and available at the time of service, it's made it much, much easier for us then to adopt other kinds of uses for data such as integrating with personal health records.

The second is to clarify that a secure download capability is an allowable option to provide electronic copies of information. That I should be able to go to a download button and get my data whenever I want it. In part, that's going to mean that today some of the data that I receive is going to be messy. It's going to be machine readable and it's going to be written for physicians. But it's better for us to give incomplete and potentially difficult to consume data than it is to wait for the data to be completely made hygienic in order to consume it.

The other reason why the download capability is important, it would be absurd to say that you're going to go to a bank, and you'll only get information on your account with 72 hours notice, and then they'll only give it to you on a CD drive or a thumb drive or on paper. We're accustomed to getting that data instantaneously. We should expect the same thing from our health systems. Thank you.

Deven McGraw - Center for Democracy & Technology – Director

Great. Thank you all very much. I'm going to start off with the question here. Joy, you weren't, and I'm directing at Joy, but essentially anybody can throw their two cents in.

There was much discussion on some of the earlier panels about how the HIPAA rule about who can access data, and particularly when patients can access their data unfortunately is still widely misunderstood, and some of the folks on the earlier panel brought up being denied copies of their data because HIPAA somehow doesn't allow them to get it when those of us who know HIPAA understand that to be true. But what do we do, even as we're sort of moving into this new era? We've suggested some even more rigorous timeframes for patients to get data when they ask for it, much less be provided it when they don't ask part of the meaningful use criteria that we've recommended.

We've got a more clarified requirement about being able to get an electronic copy if you want one, and the data is being held by the provider electronically. What do we do about this to correct the fact that we're still having problems with patients getting copies of their data when the right is clearly there, and I see that we have some material from you about state laws, and is there some other provisions that we need to do? What can we do to clarify this? It's very frustrating that still, more than five years after the right has been on the books, that there's so much misinformation out there, or lack of compliance.

Joy Pritts – ONC – Chief Privacy Officer

Well, in my former life, I had a Web site that had guides on how patients could access their health information in every state, and so people found me, and I heard a lot of stories about people who were denied access to their information. When you talk to a lot of people about why that's happening, it's usually an excuse because the provider doesn't want to give it to them. So they're using HIPAA as a shield.

I think that there are two things that need to be done. I think that there is a certain amount of, still, lack of knowledge about the rights that patients do have to access their own information and how broad that right is. There are a couple of areas where there are going to be educational campaigns that the Office of the National Coordinator and OCR are going to be undertaking in the upcoming years. One is through the regional extension centers, which will be providing implementation guidance to providers who ... reach meaningful use, so that is one avenue for reaching providers in a very efficient manner with a consistent message.

The flipside of that coin is making sure that patients are well informed of their right of access and giving them the tools so that when they meet with no, they can point to something and say yes, I do have that right, and here is where it says I have that right. And that, I found, in my former life, to be a useful tool for consumers to use would be to copy something and take it into their office and say, excuse me, but have you seen this. And having it be from a source such as HHS was quite effective, so there is, under ARRA, under HITECH Act, OCR is in charge with doing consumer education on the patient's privacy rights, and I can't speak for them because I'm not grading their communication campaign. But the right of access is considered to be a right of privacy, and will probably be addressed in that.

Deven McGraw - Center for Democracy & Technology – Director

Does anybody else want to opine on that one? I mean, one good thing, the download button that you mention, Cris, and I'm one of the people who is also involved in the consumer engagement workgroup. It occurs to me that that's – I'm wondering whether – let me step back.

I don't think there are very many sort of technical or legal obstacles to be resolved in getting that button in place. I'm wondering whether we have some cultural issues to resolve. In fact, what is the real obstacle to sharing data is more one of culture than one of true legal obstacle. Making the button available, if people don't use it, or employ it, isn't going to get us too far, I fear. So I wonder what you think about, again, ways to encourage, not just to make the law clear, but the access to data point just was hit home so hard by the earlier panels, but I really want to get to some sort of practical ideas for making it happen.

Cris Ross – MinuteClinic – CIO

You can certainly imagine counsel for a hospital saying you can't share this data because it hasn't been reviewed. You can imagine the institutional issues, as you talk about it. Gosh, I've got all this messy data. I don't want to make this available to a patient. It's going to make me look bad or it'll cause some other sort of problem that you can imagine. I think there are technical issues, and there are legal challenges, but I agree with you that they're insurmountable.

Part of the other issue is that I think we're really making the perfect the enemy of the good, that we're really trying to think about how to make the data completely computable, completely semantic, interoperable, and all sorts of challenges that I think are unachievable. And if they are achievable at all, it's going to be in the hurly-burly of the marketplace, not in the quietude of the data cathedral where we figure it all out before we can make it available. So I think we should simply accept some noise and make it a common part of practice.

Deven McGraw - Center for Democracy & Technology – Director

Carl?

Carl Dvorak – Epic Systems – EVP

We've worked through this issue with a number of providers through the years and have many millions of people actively looking at their shared electronic health record online. One of the things that you realize is that people are very nervous about the physician notes, and someone commented on this earlier. Many of those notes are written either for themselves to remember or to another physician. They're concerned that they're a bit more cryptic, a bit more sparse sometimes than a patient would actually interpret, and they fear the confusion that that would generate.

There's also a lack of elegance, right? Morbid obesity is not something you want to see in your chart. You'd rather see overweight or something like that, so there's a sense of how will the patient perceive what I say about them in clinical terms. That creates some worries, so people don't generally feel comfortable with the physician notes being exposed. And I think if you're cynical, the third reason is fear

that someone may discovery gaps in care because, as we all know today, in a complex patient who is traversing multiple health systems, there probably are a lot of gaps in care to be concerned about.

Deven McGraw - Center for Democracy & Technology – Director

That's helpful. I don't know. Which one of you guys had your tags out first? David, go ahead.

David Lansky – Pacific Business Group on Health – President & CEO

Thanks, Deven. Thank you all for your testimony and for coming. There's sort of a subtext that we haven't quite elevated to an explicit challenge to ourselves yet, which is the longitudinal record that cuts across the silos. The way the statute provided funding and the infrastructure, it tends to reinforce some of the ambulatory care and hospital silos that we have, and that's where the money goes, it's where the product market and the vendors have been.

And I'm wondering. I can imagine three medium-term, the five-year, ten-year timeframe solutions to the longitudinal record problem that have surfaced, and I'm going to ask for your reactions and guidance to us about this. One is a single dominant provider system captures essentially all of the relevant data about the patient for a long time, and certainly some of the large, integrated systems like Group Health and Kaiser, in effect, seem to operate that way. I think Partners calls their health record a longitudinal health record, if I remember right. That's fine as long as the patient remains largely getting their care from one dominant system. You could imagine that system capturing other relevant data about that patient in building a longitudinal, multiparty record.

The second model is this consumer-based repository model like we have with HealthVault and Google or Dossia, and so a third party is scooping up, vacuuming up all the data under patient control and management. And a third model is something federated, which we haven't seen that much of, in which the data basically stays where it is and is accessed and acquired through an HIE record locator service, some kind of a mechanism on demand. But each custodian keeps it.

And I think those, as I try to think about the vision we started the day with, and certainly Regina and others talking about the importance of accessing a longitudinal, comprehensive record. To get to that vision we've all endorsed, are we going to have a pluralistic set of environments? And, as we start thinking in our work about what the standards should be, what's certified, what the functional requirements are, what the incentive payments are linked to, what hooks do we need to be looking for in both the products and the installations to get us to a longitudinal health record infrastructure?

The title of our section here is infrastructure, so that's what got me thinking. And you've all got different pieces of this puzzle, I think, so I'd appreciate your reflections on whether even this model is the right way to think about it. And if it is, what are the policy hooks that, in the next two and four years, we need to start putting in place to enable a patient to have a longitudinal record?

Joy Pritts – ONC – Chief Privacy Officer

One of the essential components, I'm speaking now not in my capacity as chief privacy officer. I always have to make that clarification because I'm not authorized to represent, you know, say anything from that perspective at the moment. But from a researcher point of view, from what I was looking at in my past life, one of the components that you're missing is the data. And if you have a five-year record retention period in some states, you're not going to have a complete, longitudinal record. The record retention laws are all state based. They're not federal based, and they do vary widely, so if a patient has moved from state-to-state, you might even think you have a longitudinal record when, in reality, you just have little pieces from various years, and you might be missing entire eras of somebody's life.

David Lansky – Pacific Business Group on Health – President & CEO

Yes. I'm sort of curious about this in the sense of when you do large, clinical trials, which is sort of my background, we don't have this problem. We're able to follow patients from around the country from different systems in a longitudinal way, and we either pull data from their system, or they send us data. And you know what the data elements are that you want. You know the longitudinality of when they're collected. And then they go into a queryable database that allows you to generate your table one or figure one or whatever.

The notion, I don't know if it's the unique identifier issue or what it is, where we get away from the Kaiser system versus the community-based system versus HIE, etc. It seems like the unique identifier initially passed legislation, and it's always been revoked every time we've sort of come back to this issue.

What is it that we want to answer in the longitudinal record is one thing I would ask, so what is the question? So to have longitudinal mishmash isn't very helpful. So the records, I think, in healthcare without trials and specific data fields, or if you're following process measures or things for pay for performance demonstration project, you sort of build these things in because that's ... the system to cost share in some project. But it's really not talking about population health and management of a system that benefits the many and is the detriment of none. But I'm troubled by the lack of the ability to do this when we're paid to do it for a trial, and we can't do it in everyday clinical practice across systems.

There are many ways we've pulled data using JPL, things from NASA has got some tools, using your own Web based systems and your own centralized database or pulling or pushing. And yet, when I think about trying to communicate with the organization in my own hometown of a different hospital, it's impossible.

Carl Dvorak – Epic Systems – EVP

I think I can add to that a little bit. I think the choices that you enumerate, David, are, to some extent, a set of choices based on the context we live in today. I think what we're going to see evolve for the future, and a lot of this depends a little bit on where the world goes with patient medical home and things like that. But I think going to find that a health system who is responsible for a patient, even if it's just temporary, even if just for two years, three years, or maybe even a single episode, I think what you'll find is that they will in fact pull all available data that they can, and they will process that into record because, without that data, they really can't utilize things like expert systems, decision support. They can't understand, to do the analytics, you would need to do to make the kind of outcome differences we hope to make through automation. You need all the data, not just a glimpse of the data.

And the identifier issue cuts across all the models, right? It doesn't fundamentally advantage or disadvantage any of the models. You still have the issue of patient identification across health systems they might have been seen. So I don't think you'll have to be a Group Health or a Kaiser to get that benefit. What'll happen is when a patient presents, you will go out, and you will pull that data in, and you will form your organization's perception of that patient, and you'll let your rules and your processes and your computerized agents run on that to help best inform care for the caregivers that you can.

David Lansky – Pacific Business Group on Health – President & CEO

So that implies to the third of the ones that I listed, more of a federated environment.

Carl Dvorak – Epic Systems – EVP

No, it implies the first. I think each – there won't be one mega repository that someone has. Everybody will have their repository, and that'll be the home base from which they do their care. They will get it from other people's health systems, but they'll bring it down.

I think one thing people lose track of is that that data actually morphs through time. People's understanding of a patient's problem actually changes as you get a deeper understanding of what really is going on. So not all data is actually even in the playing field of how it's used in decision support and in a clinician's understanding of it.

Cris Ross – MinuteClinic – CIO

If a patient happens to receive all their care through a large, integrated network, that's great, and that may be a perfectly sufficient solution. I think there's some other data that suggests that that may not be the case. People move. People are interested in consumerism increasingly in healthcare. They're interested in quality, convenience, price, other attributes, just like they buy other things. So if people aren't receiving data from a single dominant system or collection of systems, I think we've got to talk about the federated model that you suggested, David.

I guess the thing that I would press on a little bit is tease out the question of do we need a longitudinal record for all data for all patients at all times, ready and assembled at a moment's notice? I mean, the use case of sort of the emergency room crack the class and solve the problem is, I think, an extreme use case and forces on us more cost than we want to accept. So I think we've heard, in a lot of settings, that one of the most important things that you do want to have a hand, right: medication, labs, images, maybe a problem list, maybe allergies, although there are issues around how you encode allergies, maybe procedures that have been performed.

In some ways, if it becomes easier and easier to make this download button happen, either by the consumer or by their providers at the request of the consumer, then assembling a longitudinal record in time to deliver care in an efficient, low cost, high quality kind of way becomes easier and easier. I think the idea that we either have to have all data available in one giant repository at any given time, or that we need to somehow force the market into a medical home, if the consumer wants a medical home, more power to them. But if they don't, we need to provide other means for them to be able to assemble the data as they need it to enter some new sort of treatment.

David Lansky – Pacific Business Group on Health – President & CEO

Where does that download data button sit, and how is it you collect it from different sources, and how it is interpretable? I'm still not understanding.

Deven McGraw - Center for Democracy & Technology – Director

It's just – and for those of us who are participating in this effort, we're still flushing that out, but essentially it's a way for a single data holder to respond to a patient's request to get a copy of the data that—

David Lansky – Pacific Business Group on Health – President & CEO

From that particular provider?

Deven McGraw - Center for Democracy & Technology – Director

Right, from that. So in other words, if you wanted to use that as a mechanism for gathering all of your data, you would have to go to each location to get it unless that button were somehow available through a health information exchange where, if you hit the bottom for the exchange, any participant in the exchange is data. But that still seems, I mean, I think we're ... that the first step is being a simple way, and not a requirement, but a simple way for copies to be able to be given to folks who ask for them. I think one of the common examples is if you have a patient portal into the record that currently patients can view, but maybe not download a copy or screen scrape, that this might be an easy way to get them a copy of their data at the touch of a button.

Cris Ross – MinuteClinic – CIO

I'd offer the example of the best working example, obviously, is medications, right?

Deven McGraw - Center for Democracy & Technology – Director

Right.

Cris Ross – MinuteClinic – CIO

SureScripts maintains a master patient index to which you can get access to medication history pretty reliably and pretty thoroughly. There's clearly some challenges with it, and there are reasons why other segments of the healthcare industry are not the same as the pharmacy industry, but there are some usable examples that essentially in real time, MinuteClinic can go get a copy of a patient's medication history with their permission in sub-second kind of performance. It's truly a federated model. SureScripts doesn't hold that data. They are a switch that points to where the data resides with the PBM or the pharmacy.

Deven McGraw - Center for Democracy & Technology – Director

Paul?

Paul Tang - Palo Alto Medical Foundation - Internist, VP & CMIO

I have sort of an out-of-the-box question or scenario. I'm worried that, well, I want to check and understand, make sure we don't have a hammer problem. In other words, looking for a nail, when what we have in front of us is a screw and all the screwdrivers are tethered.

My wife is an ICU nurse. And, as you know, nursing is a 24-hour work schedule, and there's elaborate ways of trying to schedule who has to do night shift this month. On her unit, the manager tried a unique thing, which is, what do you want to do? And it turned out, they just distributed like normal humans.

To get back to the medical example, I think Dr. Weinstein gave an example, the patient with a problem that shows up in the spine surgery department, but actually had a medical problem with too many medications. And you removed the medical ... reasons, and they no longer needed what you could provide.

Are we in a policy silo? This happens to be the HIT Policy Committee, and we're looking at what nails do we need to go find when there's a bigger problem, the elephant problem. What's more potent to build yet a better carrot or to try to identify, even if it's not in the true scope of this committee, define the big – sever the leash. I know I've got some quizzical looks, but I think—

Deven McGraw - Center for Democracy & Technology – Director

The other panel got that question. I have to admit that I didn't.

Paul Tang - Palo Alto Medical Foundation - Internist, VP & CMIO

But it came through. It came through.

M

A lot of analogies....

W

Yes, can we have one more analogy, Paul, because I'm not ...?

Deven McGraw - Center for Democracy & Technology – Director

Yes. Who is the elephant, and who is on the leash?

W

Don't forget the nail.

Paul Tang - Palo Alto Medical Foundation - Internist, VP & CMIO

Would everyone, providers, patients, and the whole system work differently if we didn't have a payment system that reimbursed for the wrong thing? If that leash just tethered us to do things, and are we trying to go build a carrot when they would all go there anyway? James Ralston said earlier in his testimony. When I asked him, you said you had to go through this unnatural act to get this stuff in the system. Why? Did the vendor hold you up? He said, well, actually, to be honest, the vendor doesn't make those products because the insurance wouldn't reimburse providers for doing that.

Is it that we're trying to push them to stretch the leash more, or should we go try to figure out how to sever the leash? And so that's just sort of a bit of a question to ourselves, but maybe I could ask. There are different kinds of representatives in front of us. Which is the more potent force to go create more incentives, more meaningful use criteria, or to go find, address the leash?

I'll give one more example of that, which is in the privacy domain. We have 50 state laws at least, and a lot of that is impairing our ability to exchange data or, ironically, it's impairing our ability to protect data just because it crosses from one latitude to another. Is it that we create yet another, more state laws or more federal laws, or do we do something about the laws we have? It's the same ... of why add more things to what we already have to do instead of trying to correct some of the things in the past?

Joy Pritts – ONC – Chief Privacy Officer

Paul, I was going to refer you to the fact that they're probably going to be creating FACAs under the health reform bill, and maybe that's where you need to go sit.

James Weinstein – Dartmouth-Hitchcock Clinic – President

I was going to say, my colleagues Brian Quinn and Paul Batanna would say every system design is designed to get the results it gets. We've designed a system to get what we've got, and as a Michigan factory worker told me, if you always do what you've always done, you'll always get what you've always gotten. And so I guess, to me, studying the Dartmouth Atlas using Medicare data for years, and looking at the tremendous variation of how we do things in healthcare, IT is just another part of that problem, but could be part of the solution, but not the solution.

I like the analogy. I think we don't need – everything isn't a nail, even though I'm an orthopedic surgeon. But the fact of the matter is, what I found and what I said to you today is the patient reported data is more important to me than the MRI, CT scan, or x-ray. And there are so many patients receiving spine surgery in this country. Muscular skeletal disease is the second most common reason to see a doc in the United States, 87% increase in Social Security Disability over the last five years, most do to musculoskeletal and mental illness.

We have to start doing some fairly simple things with huge impact. So if you're talking about global health, is it treating HIV or drug resistant TB ... Paul Farmer and Jim Kim, or is it dealing with low birthweight babies and mothers in pregnancy and things like that and nutrition? Simple choices can have very big impacts, and I would argue with you, given that I've studied this data for many years now with Jacqueline Burg, Ellen Fischer, and others, that just knowing what the patient's health status is or doing health risk assessment in some organized way will inform the decision process.

Now the payment system is perverse and has to be changed. Everybody who has an individual specialty does what they do. If you go to a spine surgeon, you're likely to get spine surgery. If you go to an internist, you're likely to get something for your blood pressure or medication. If I just changed the definition of the blood glucose or hypertension by five points, we could add three million more people to the disease state of this country, or take away three million people.

I would really like us to do something very simple. All the patient's information to be used to determine their care and measure the outcome. If we knew the diagnosis, gave the patient the opportunity to engage in shared decision making or their preferences and values, and measured the effective treatment, we would know a lot more than we know today about healthcare, those three things.

Carl Dvorak – Epic Systems – EVP

I think, Paul, the other question for you is does the elephant know how to use a screwdriver. Does CMS understand the real value of e-visits and things like that? What we've seen at places that control both the provider side and the payer side, basically the provision, as well as the contracting for care, they have desktop medicine units. They have physicians who spend their day working through these online tools.

They have created the ability to take a picture and send it in as part of an e-visit to avoid the dermatology visit. They find ways to reduce, and James comment earlier today, 30% or a third of their visits now go electronically. Some other managed care organizations reported like a 25% reduction in visits. There's tremendous capacity there if we can adjust and start using screwdrivers instead of just the hammers and the nails.

Paul Tang - Palo Alto Medical Foundation - Internist, VP & CMIO

...that. If we somehow, the health reform FACA recommended that we change the payment system. Would we no longer need to have the meaningful use criteria for this area to cause that change to happen?

Carl Dvorak – Epic Systems – EVP

It depends on how they change it, I guess.

Paul Tang - Palo Alto Medical Foundation - Internist, VP & CMIO

Let's pretend it was the patient's health first, and it was something like they do in the ... world. But let's pretend there was a way, as Dr. Weinstein talked about, let's say the measures, and we got the measures right, and that's how you got paid. Would we not need HIT incentives?

Cris Ross – MinuteClinic – CIO

I think you would for maybe two reasons. One of which is the crisis in primary care that's upon us and is going to get worse as the number of primary care physicians declines and it becomes harder for people to access basic, primary care. That's the place where we're going to engage with patients around lifestyle, wellness, exercise, diet, smoking, those kinds of things before it becomes a disease where it's still a behavior choice. That segment of the healthcare industry is not automated, does not have access to data, or at least it's under-penetrated in primary care relative to other kinds of places.

The second, I'd make the argument that if in fact lifestyle diseases are a significant problem for us, and I think that's pretty clear, that the kinds of data we want to produce is in fact consumer data as opposed to provider-to-provider data. The focus may not be as necessary. I mean, we're still going to need to have providers talk to each other about how to do intervention once diabetes arrives, but wouldn't it be more

powerful to make data accessible to consumers so that they could see the kinds of precursors in their health that's going to lead them towards illness.

If we let them know what their glucose levels and their cholesterol levels were and their A1c levels were, and it was easy to get to them, and it was easy to get to a primary care physician who could perform that test, provide the data in an automated way, put it into a longitudinal record and a personal health record or some other repository. I would make the argument that that would have more affect on moving trend in disease, morbidity, and cost than maybe some of the other things we do. I think it's urgent that we keep pushing.

The last piece I guess I'd add is reimbursement reform. There's one is change the way we pay, based on outcomes for example. The other one would be a modest proposal that we look at tipping reimbursement rates between specialties. Again, primary care is under-compensated relative to specialties, and it's one of the reasons why we don't have point of care that we need to sort of be the shovel point on some of these problems.

Carl Dvorak – Epic Systems – EVP

The primary care doctors that we interact with look at what's happening with meaningful use as maybe the final demise of primary care. There are not enough of them. They don't get paid enough. They have a lot of things to do. And it feels to them, in many situations, like we're just adding on more and more requirements, more regulation, more reporting, more requirements to manage the patient outside the context of the office visit, but no compensation for that, and they're already feeling stretched.

I think if payment reform did something to close the flow a bit more of unnecessary diagnostics and funneled those economies back into primary care, make primary care a healthy living for people and compensated them for management beyond the five minutes in an office, I think the dynamic would just fundamentally shift. Would we still need HIT? I don't know. There may be ways of that new system might be optimized to our disadvantage that we'd want to at least create some guidelines for. I feel like we have to get 10,000 little levers perfect or we can work on the one or two big levers that everyone sort of understands creates the fundamental machine of our health system.

Deven McGraw - Center for Democracy & Technology – Director

George?

George Hripcsak - Dept. of Biomedical Informatics Columbia University – Chair

I guess this ended up being the same question as Paul's, but at a less philosophic level.

Deven McGraw - Center for Democracy & Technology – Director

Does yours have an elephant in it?

Paul Tang - Palo Alto Medical Foundation - Internist, VP & CMIO

Does yours have an elephant in it?

George Hripcsak - Dept. of Biomedical Informatics Columbia University – Chair

No, partly an animal. Maybe one alligator, but that's it. So we're doing meaningful use and patient engagement. We need to author stage two, you know, objective soon. And we have the sector of the vendor community represented on this panel, so that's a good thing. And so the question comes down to incremental versus really making a big change using concrete objectives.

Carl Dvorak – Epic Systems – EVP

I choose to be an innovator today, not a vendor.

George Hripcsak - Dept. of Biomedical Informatics Columbia University – Chair

Thank you. What feasible – and some of it has been answered a little bit. I can see James' answer, but feasible requests that provoke big changes would be something that would be a nice thing if we could accomplish that, or something that the community could probably swallow, but actually provoked a bigger change, but not going to healthcare reform. Doing it within the meaningful use imperative. So there are things we're going to have to consider.

Are we leaning more towards using some kind of quality indicator looking thing to improve patient engagement that is measuring something? Is that another, lumping something on top of the primary care provider something else to report on versus an objective that pulls about some infrastructure change? That's more about making sure the data gets shared. You can kind of do the quality indicator ... so what is the panel's kind of feeling about where we should go with stage two objectives with regard to ... we all want to provoke big changes, but there's some feeling there has to be something feasible, or people will ignore it.

Carl Dvorak – Epic Systems – EVP

I reminded of reading the latest Malcolm Gladwell book, *The Difference Between Mysteries and Puzzles*. More data helps you solve a puzzle. More data just makes a mystery even more mysterious. And I respect that you guys have to solve that puzzle. You have to put specific regs down. I would answer that if you required for stage two or stage three a requirement that provider offices be able to message back and forth with patients, and maybe for a stage three, require a more formal e-visit capability built into an electronic health record connecting the doctors through a PHR to a patient. That would be a concrete benefit that then CMS could work with to further programs for electronic encounters rather than face-to-face.

The basic provision of a patient useful data file to them, so if they wanted to take their data and do something, they could. And then the fundamental ability to review their results online and have access to their trending information is fairly straightforward to do, and I think it would make a difference in patient engagement.

James Weinstein – Dartmouth-Hitchcock Clinic – President

I would just say, as a practicing physician today, I think it's really hard to do what you just said. I mean, I'm pretty busy seeing patients and trying to just get people in the door, let alone sit on my computer and e-mail a patient e-mailing me at the same time. It's not about the money. That's the problem. It's about how do we have fun in doing what we signed up to do in our hippocratic ways in taking care of patients if the fun is gone.

The notion of patients being a partner in this was not to put more burden on the physician. The notion was that I need to get the patient information in some way to help me with my medical record and practice, to be useful at the point of service, to manage their problems today, to aggregate that information for a population of like patients or cohorts over time, and then be able to measure value of what we're actually doing and treating.

As you all know, many of the things turn out to not be effective after they get out of the FDA trials, and everything else. It's only after we have population based data that we actually, as a nation, find out that we actually might be hurting some people. That has to end. We have the ability through large databases with Epic and others if we actually could use that data in some useful way to start to manage care.

I would argue, the primary care doctor is struggling because the payment system says you only get paid on how many patients you've seen and what you bill, which is really hard in primary care, and to add on, meanwhile, keep in touch with me by computer is really difficult. Yes, technology will help. We're doing some work with GPS, even looking at the topography of where people live, trying to predict their utilization of resources. It's very interesting stuff, but still way out there.

Can we just make the doctors' and patients' lives a little better, incorporate what they want to tell us, and to manage in them today, measure it, and then pay for the value? Without that measurement, we're going to keep paying for systems that don't work.

Deven McGraw - Center for Democracy & Technology – Director

Neil has a follow on to that, and then we're getting to you, James.

Neil Calman - Institute for Family Health - President & Cofounder

I was just going to say ... I'm not sure that your experience and mine are the same because I don't do spine surgery. I know it's not the same. But I can tell you, on the primary care end, the things that are being put into computer communication with patients is all stuff we do anyway, except when you can do it asynchronously and more efficiently, you can do a lot more of it in a lot less time, so it actually doesn't increase the burden. It actually just changes the context of the work. And I think it's important to realize that this may play differently for different specialists in different ways.

Right now, in the old days, I would finish a day's work and be handed 20 patient messages. And now that stuff is coming in during the day. I can see it. I can route them. And by the time the day is over, maybe I have to answer one or two patient e-mails, but it's not the same as it was, and people are getting a lot more efficient response to their questions, and I think both on the patient side and the provider side, there's more satisfying work because your work is focused on things that are critical.

I guess I felt the need to respond to that because I think it's important that this is not going to play out. Maybe that's something we need to learn is that the response to different provider communities is going to be very different depending upon what the nature of their work is.

James Weinstein – Dartmouth-Hitchcock Clinic – President

Yes. I would say that that last point is the key. I mean, I run an organization now with 900 docs and 10,000 people, and each of the primary care practices are very different. If you have a care coordinator who can answer some of your messages, if you're not paid on volume, I agree with you. But it is difficult to get access and people into the system that needed an effective way in some of our practices. And the ones that are set up effectively, i.e. the Group Health model or the Geisinger model, it works pretty nice, but that's not the average practice in the United States.

Deven McGraw - Center for Democracy & Technology – Director

James, go ahead.

Jim Figge – NY State DoH – Medical Director

I'd like to raise the idea of building infrastructure to provide useful decision support tools to patients. I don't think the patients always want a dump of all their raw data, and in fact, in some instances, that might be counterproductive. Let me give you an example. If I were a 60-year-old male who just had a PSA test come back slightly elevated, and my father had prostate cancer, I'd want to know what's my risk of prostate cancer, so I don't need more than about five data elements and a decision support tool to do that calculation for me, so that's the data I would want in that particular situation.

And I know, James, you've submitted some very nice information here in writing from Dartmouth about patient decision support tools, and I just wondered if the panel could comment on the utility of those tools, where are we now, what's the state of the art, and should we build more infrastructure to develop these tools?

James Ralston – Group Health – Associate Scientific Investigator

I'll just mention what was in our report. We have built various calculators, and you see them on the Internet for various diseases, osteoporosis and others, but we've taken our national data so that a patient who is seeking the decision about spine surgery would have a shared decision making tool, getting information from independent sources. But then there's a calculator they can answer seven questions on, and it will give them the probability of success with surgical or nonsurgical treatment over time immediately in the clinical visit, and they really love that. And that, once we're done with the final testing, will be available for free on the Web site.

Cris Ross – MinuteClinic – CIO

There's a fair number of free consumer oriented tools that are available today, right? One thinks about things like WebMD or Health Grades, and the number of searches that happen on search engines to help people find that data.

At least our experience at MinuteClinic is that our adoption rate of the number of people who want to access their medical data is pretty low, and the number of people who want to do something with the data is pretty low. But I'll give one sort of anecdotal example. We offer very low key suggestion to a patient that they can do something with their data, and we offer three services: Google Health, Microsoft HealthVault, and Keas, which is a new company doing health coaching.

What we found is that the uptake of the Keas service is surprisingly large given the brand name of the other two offerings we provide, and the only difference between them is that Keas is presented to them as a way to receive some advice about your health as opposed to a way for you to manage your data around your health. And I think there are consumers who want both, but a very anecdotal piece of evidence is that given the same pathways, people are interested in advice rather than data.

Jim Figge – NY State DoH – Medical Director

Right, and I agree with you that there are all these free tools on the Internet. The problem is that a given patient doesn't really know the validity of these tools, so you can go find something, and you plug numbers in, but you don't know if what you're getting back is really valid. So I'm talking about building a validated infrastructure that's used in conjunction with the clinician to help make mutual decisions about critical disease states. In my prostate cancer example, I want validated data coming back to tell me what my risk of prostate cancer is, and I would like my clinician to be part of that process so that we can mutually discuss this data, so that's kind of what I'm getting at.

Carl Dvorak – Epic Systems – EVP

We do see sides starting to blend those tools into the portal. The benefit of the Web is that it is a fairly open environment, so it's relatively straightforward to wire in additional calculators and even through Web services to pull certain data from the chart to default into those calculators, so we see sites do that, and they'll validate the calculators with their physicians inside. I think that's just going to be the next growing trend. I think we're seeing just now the explosion of patients having access to the data online, and that's the next natural step.

Jim Figge – NY State DoH – Medical Director

But should we make it a meaningful use criteria to have the clinician?

Carl Dvorak – Epic Systems – EVP

No, there are plenty of criteria already.

Jim Figge – NY State DoH – Medical Director

Have the clinician make that data available to their patients in a more or less automated fashion and incorporate it into the clinical encounter.

Carl Dvorak – Epic Systems – EVP

I don't know that you need to because it's the next logical progression. If you make it requirement that they have patient data accessible through a portal, it'll happen. You can make a requirement if you want, but I suspect it'll be an unnecessary one.

Deven McGraw - Center for Democracy & Technology – Director

Christine?

Christine Bechtel - National Partnership for Women & Families – VP

I have a question, and I think it's for Joy. As we talk about starting to make data more liquid and movable, when we talk about personal health records and personal health platforms, etc., being able to store data in there. Some folks have raised some concerns about barriers that are presented by how the PHRs themselves might use the data, secondary uses. And so, you know, when you load your data in, you've got a screen that says this is our privacy policy. This is how we may or may not use your data.

Can you just describe for us sort of what's this data play. What are the key issues? And what is it that we might need to be aware of, as we're trying to make data more available, and it's, in all likelihood, going to be managed in some sort of a platform or a PHR, some sort of a thing? What are the sorts of privacy areas that we need to keep top of mind?

Joy Pritts – ONC – Chief Privacy Officer

It's a pretty complicated landscape to navigate from a consumer perspective because it depends on who is offering the PHR, what rules apply. So if it's a portal into a provider's record, one set of rules apply. If it is a PHR that is being offered on behalf of a covered entity under HIPAA, that would be covered by HIPAA also. If it's being offered independently, then you have a different set of rules that apply. So from a consumer perspective, it's pretty confusing to know if you use one of these, what the person, what the organization can actually do with the information.

There have been the breach notification rules that came out that deal with PHRs that are FTC issued it's set, and HHS issued it's set for the covered entities, and there is a study that is due on who should be governing these, what they call, non-covered entities because they're not covered by HIPAA right now. And so that is a discussion that is very, very timely, and is taking place, but it has not concluded yet.

One of the – I looked at a lot of those PHR models when doing some research in my prior life, and one of the things that makes it confusing for an individual is not surprisingly a lot of that information is buried in a lot of different places on the Web site. And it's not necessarily intentional. It's just the way Web sites are developed, so you get some pieces of information on how the information can be used in the terms of service, and then you'll get other pieces of information in the privacy statement. And in order to get a complete picture, you'd have to read them both. If you think for one minute that there are more than five people in America who have actually read those, I would be willing to bet you on that one because nobody reads them.

M

Deven did.

Joy Pritts – ONC – Chief Privacy Officer

Did you, Deven?

Deven McGraw - Center for Democracy & Technology – Director

Do I read them? It depends on how much I want it.

Joy Pritts – ONC – Chief Privacy Officer

But most people just, you know, they want to use it. They click, I agree. And so even, and the same is true. It's not just these products. I mean, there have been some major social networking sites that have had similar issues where they thought that they'd done a good job telling people what they were going to use with their data, and when people figured it out, they were really ... about it because the notification to consumers is not quite where it needs to be yet.

And I think that's something that I think, Paul, you've raised a number of years ago, which is also something that I believe is being looked at is to kind of try to find a standardized format for bringing to the front the top issues that consumers should be concerned about or would be concerned about, and maybe providing those in a uniform fashion so that kind of like – I think the way you were referring to it was as a soup label, right? The nutritional label on a can of soup, it tells you. It's in a uniform fashion. You know how much sodium you're getting, regardless of what product you're looking at, so there are things that need to be done to make it much clearer to the individual as to how their information is being used. The information may be provided now, but it's not easy to find.

Christine Bechtel - National Partnership for Women & Families – VP

Just to briefly follow up on that, so I'm sure you'll get on that next week or so, right, Joy?

Joy Pritts – ONC – Chief Privacy Officer

Actually, we're already on it.

Christine Bechtel - National Partnership for Women & Families – VP

Good. All right. In the context though of meaningful use, the point of my question is we talk a lot sort of in the theoretical or at the principle level of wanting privacy to be an enabler in building trust and not wanting it to be a barrier. Yet, sometimes when we go to talk about moving a policy forward that would put more data into a vehicle like a PHR, privacy gets raised as a barrier. Is there anything in the context of meaningful use and what we might recommend?

I hear you on the consumer notification piece, but I'm just wondering if there are any things that we might be able to recommend that, in the context of meaningful use, either a provider? I mean, it's mostly going to be a provider action because that's the locus of meaningful use. But I'd be curious, and I'm happy to follow up offline just so you can have a minute to think about that, but it's an important issue that I think we need to keep top of mind.

Deven McGraw - Center for Democracy & Technology – Director

Don't forget that you also have a privacy and security workgroup that's going to be working on that issue.

Christine Bechtel - National Partnership for Women & Families – VP

That would be great. So you guys are going to take...?

Deven McGraw - Center for Democracy & Technology – Director

We have to get to Charlene because she has a question and we're running out of time.

Charlene Underwood - Siemens Medical - Director, Gov. & Industry Affairs

....

Deven McGraw - Center for Democracy & Technology – Director

You know, it's a dilemma when you think about what additional provisions we are going to need to put in place to meet the – to build the consumer trust, particularly where we have a lot of new tools and things that didn't exist in the environment when HIPAA was created. But whether you do that through meaningful use or you capture a snapshot in a small group of providers, or whether the more prudent course is to create a set of rules that would apply, whether you're meaningfully using or just plain using, I think, is an open question that we have talked about and will continue to talk about, as we sort of think about, number one, what protections should be in place? What are the various tools for getting there? And what's the best way to do it? And if we can't do it that way, what's the next best way to do it?

Carl Dvorak – Epic Systems – EVP

I think it's interesting that HIPAA has finally permeated the mind of the average person because you hear it, the folks who brought up direct patient examples spoke of hearing it. And although it's not a perfect understanding of it, it has gotten to not everybody, but to many, many, many people. I think the trick is in terms of what meaningful use could do or not do to make this better or worse. If you force that data outside the confines of HIPAA, patients will need to understand what they might be exposed to. I think most people realize that if you chose, you could put your health record on a billboard by the freeway. That would be your personal choice.

What they don't know is what might happen to it that they don't expect to happen to it when it starts to float around. I think, in the absence of very crystal clear rules as to what might happen to it or be allowed to happen to it, they at least need to understand that they're moving it from a HIPAA covered entity to a place where those rules no longer apply, and they really should be concerned about what the new rule set looks like in the new place. They're very different rule sets sometimes.

I know there's work now to try to create a rule set because there really wasn't one. If you didn't read the 32 pages of legal text, that's too bad. But I think, for the time being, we have to be careful because if we push that information across that line without patients truly understanding or being able to anticipate what might happen, we may come back with sort of the Facebook affect of, oh my, gosh. You did what with my data?

Deven McGraw - Center for Democracy & Technology – Director

Right, and I think that's a challenge, right, because the healthcare system, in keeping it inside the healthcare system, we just spent a lot of time talking about payment policy. The healthcare system is not innovating, right? The private market is, and so, I mean, allegedly at least, particularly ... update it, so that's exactly the crux of my question.

Carl Dvorak – Epic Systems – EVP

I think it's a wrong statement. I think health systems do innovate. You ought to see what they do at optimized payment from CMS. It's amazingly innovative.

Deven McGraw - Center for Democracy & Technology – Director

Exactly. That's my point. Yes.

Carl Dvorak – Epic Systems – EVP

And I think that the other folks who innovate differently are innovating around advertising. You ought to see the creative things they do to advertise and to target products and to know who you are from time-to-time when you visit different Web sites and they share it about you behind the scenes. There's lots of innovation out there. I think the real question comes back to, to what end.

Deven McGraw - Center for Democracy & Technology – Director

Right.

Carl Dvorak – Epic Systems – EVP

Health systems are amazingly innovative.

Deven McGraw - Center for Democracy & Technology – Director

And to this end, not so much.

James Weinstein – Dartmouth-Hitchcock Clinic – President

Yes.

Cris Ross – MinuteClinic – CIO

But I don't think we need to be working so hard to search for alignment. Maybe this is over-simplified, but we had two panels this morning where you had pretty vivid testimony that said just give me my data damn it, period. I want my data. And that's pretty compelling if we didn't have meaningful use anyway. And there's this group of really distinguished folks listening to consumers say give me my data damn it. It should have an impact on us.

The fact that the things that we need to do to satisfy that desire also supports the other things that we want to accomplish in terms of driving innovation, improvement of quality, and liquidity of data and all the rest. Maybe it just seems terribly obvious. I understand there's clearly risks in taking the needle way too far and being cavalier with people's privacy and security and making people feel like they don't want to play because they can't trust any of the players. But I just don't think that's as big of a risk as the risk of inaction and our inability to listen to patients.

Deven McGraw - Center for Democracy & Technology – Director

Charlene...?

Charlene Underwood - Siemens Medical - Director, Gov. & Industry Affairs

Thank you, and thank you to the panel. I was actually going to follow on. I knew there was a status, Joy, relative to trying to simplify, creating that food label concept, because I agree. I think there is a potential trust issue there. I know personally, in terms of the patient engagement. I don't want to put any health data, because again I'm a little educated here, out in filling out any survey because they always ask for this stuff because I don't know what's going to happen to it out there.

So I think that progress forward to make it clearer in terms of your protections and know that you can go someplace, and all those sets of things are going to be crucial to moving the industry forward and ultimately the patient engagement because there's going to be forces that we're going to want to be able to engage with outside of the health system, which we trust more today. But we're going to have to watch that trust, as we move through this course in terms of engaging patients. So I would support continued focus on simplifying and making it readable and creating the means to educate.

Deven McGraw - Center for Democracy & Technology – Director

I think we've reached the end of this time. Thank you very much. I'll let the cochairs thank the panelists as well, but you were a terrific panel to moderate. Thank you.

Paul Tang - Palo Alto Medical Foundation - Internist, VP & CMIO

Now we have a little bit of time. Tomorrow, obviously we're not going to present our report from today, but we probably should give them an update, so maybe I'll give people time to collect their thoughts, and what would you like us to report on at tomorrow's policy committee meeting as sort of takeaway observations, findings, whatever, obviously not recommendations yet?

Christine Bechtel - National Partnership for Women & Families – VP

I heard two things that I think are important, and one thing that I want to tackle. The two things that I heard that were really important themes throughout the panel today and, Paul, I think you did a good job earlier of characterizing this sort of need to reorient the system so that it is much more oriented around patients needs, patients health status, patients own goals for their healthcare. I think Jim Weinstein did a great job talking about the importance of that and that there are some very simple ways that, through meaningful use, that we can have an impact in those areas.

But it is the whole sort of gestalt that doesn't, I think, in my mind, exist as a whole today in any one place. There are wonderful examples, and we heard a lot about them today of people who are doing pieces and parts of it. So that system reorientation, I think, is connected to payment, which I want to come back to in a second.

The second thing that I heard that really resonated with me is the importance of focusing on a sense of community between providers and patients. And I heard it in two ways. One, I heard a lot of folks talking about the key to patient activation being developing and supporting those connections between patients and providers, that communication channel, the ability to go back and forth, the ability to have a relationship there that is meaningful that cannot happen in a seven-minute office visit. I mean, it just can't. So if we think about all the time we've spent together developing our relationship, it doesn't happen in a seven-minute visit or a five-minute phone call. I think, Neil, you were really eloquent in talking about that.

The clear role of technology in building that community is evident to me, and I think it's going to take us to thinking about technology and meaningful use in a way that starts to get us out of a box of certified EHRs and EHR modules. And I think we should be open to that. And I think that is a key driver as well for that sort of broad reorientation of the healthcare system.

The other side of that that I heard was some discussion about behavior change and compliance, which, for the consumer community, it makes my hair stand on end a little bit. And I think we have to move away from that orientation that says that this is about a top down, one sided approach, and me telling you what you ought to do, patient, and you going and following up with that, and complying with your treatment plan, and figure out how you use technology as a tool to better support, again, those connections and that sense of community and the orientation that is around the patient.

The last thing that I want to say, and I was going to say ... be quiet, but we've heard that before, is the reimbursement stuff. And I have a lot in my head I'd like to say about this, so I'm going to try to limit it because I think it'll come out jumbled if I don't. The notion that this is about payment reform and that that's really what we need to drive the system, I understand that, and I think we are all, certainly including the consumer community, working in different ways to drive payment change. Eric Dishman talked about the Center for Medicare and Medicaid innovation in health reform, and the promise that that holds, and we're very excited about that.

But I also don't want to let that be the constraining factor. I think it's oftentimes the constraining factor, and I think there are a lot of factors that constrain us. And payment is one. Workforce and training is another. The size of the primary care workforce, but also how we train them around patient centered care, which I don't think we really do a good job of today. So there is a lot of limiting factors.

But when I think about HITECH and I think about the framework that we've developed for meaningful use, it's not about technology. If it was, we'd have a very different framework. And so I think that's okay. And I kind of kept hearing a tension, and it came up most often in the payment reform discussion between, gee, is this really in scope or out of scope? Is this really health IT? Or is this broader healthcare, payment reform, health reform, etc.?

I think that, if I think about the E and the C in HITECH, it's about economic and clinical health, cost and quality, so I think we ought to use the tool we have at our disposal, which is health IT, which is meaningful use incentives, understanding their limitations, but not be so constrained by what we try to achieve. That if we orient our thinking around really what is patient centered care, then that takes us to using health IT in a different way then I think we've historically at least the healthcare community has used it. I want to say that I strongly support that coming back to that reorientation and understanding the limitations, but not being completely constrained by what's in scope or out of scope, really leveraging the tool that we have in front of us.

Paul Tang - Palo Alto Medical Foundation - Internist, VP & CMIO

David?

David Lansky – Pacific Business Group on Health – President & CEO

I found it be a very enlightening, inspiring day, and I hope we can capture that in the report tomorrow at several levels. One, I think, as Christine concluded, I have a slightly different spin, but the same general takeaway that there are lessons form today for the strategic planning work that the HIT Policy Committee is doing, and you're involved in, Paul. And it goes beyond the framing as a learning healthcare system that the committee has undertaken to a much larger transformation even beyond the healthcare system in the way we think about it, and that would include the payment, culture, technology, legal dimensions that were all raised in one form or another today as the opportunities or barriers to getting to the decision we started with this morning. That's one thing on the side.

Personally, I am interested in Eric's proposal that we think about shifting a large proportion of care to the home or whatever you want to call it outside of the traditional settings, some very expensive settings that we use now, and finding some way to articulate that as an objective. And if you do that, then I think there are a number of levers within the ARRA structure that we can begin to exercise toward that goal. Specifically today, I heard two pathways that made some sense to me, as we look at 2013 and 2015. One is one meaningful use of EHR is to release the data, so one meaningful use is not to use it yourself, is to give it to someone else to use in a structured and portable way and so on.

The second category of meaningful use are about how do we influence the behavior of the health system and the health professionals. Those are the uses we tend to think of more often when we think about CPOE or decision support. In that class of uses, I am inclined to think that some kind of new set of measures that I'll call outcomes measures of one kind of another are a way to reward sharing of information with caregivers, families, and patients because it helps you achieve a measurable outcome, whether that's a patient experience outcome, a clinical outcome, or some kind of health status outcome. We'll get into that at some point.

But it's interesting that I think the way CMS approached the 20 or so medical specialties for quality measurement reporting might provide us a template to deal with the segmentation issue that a couple speakers brought up. That is, we may not need to sort of boil the ocean with just one match, but we can try to break it up into, I think, as Chris suggested, or there was some suggestion of separating the chronic from the general population. We may want to think some more about using some framework for outcome measurement that is somewhat different for certain types of care, specialties, or populations, but which maps into the structure we're already being given by CMS as a way to get to some practical 2013, 2015 objectives that are not hard, not a new burden, not a new strategy, but layered into our current system.

Two other quick thoughts: The challenge we heard today about capturing patient data into the record, whether it's in structured or unstructured form, I think we have to give more thought to. But again, I think an outcomes framework would encourage users to do that. And the last point is that I think this idea of a video patient education, some way of giving the public a feeling, a gestalt about this direction we want to encourage is worth our attention as well, and ONC's.

Deven McGraw - Center for Democracy & Technology – Director

I want to piggyback on what David said. I actually think that was a nice summary of some of the key points that came up. The data out and the data in aspect of it, so patient generated data coming in to the record, and we heard various models of how that's being done in different places in the country. Then, of course, the data out to the patient, which David said.

I think the thing that I'm struggling with, and maybe the outcome measure is the right way to get there because I certainly can't think of another way. But in essence, we saw today a variety of successful models where the technology is being used and the communication flow is bidirectional, and the providers are seeing better outcomes, and their patients are happy with what they're seeing. But it wasn't a one-size-fits-all approach. And, in stage one, we had some needs that we needed to fill in terms of getting data into the systems and getting the systems onto the desks. But I think, when we think about what meaningful use in later stages ought to be about, we ought to be thinking of criteria that lend themselves for some flexibility and flexible approaches.

Maybe that's one way to get the primary care physicians not to think of this as yet another list of things that they need to check off in order to get their financial incentive payment, but instead as sort of here's a set of tools and a set of goals, and you figure out what's the best way to reach that given your patient base and what they're experiencing, and your particular practice. That's what I would say. We didn't have the ability to be flexible. I'd like for us to find a way to do that in the next set of criteria.

Paul Tang - Palo Alto Medical Foundation - Internist, VP & CMIO

Neil?

Neil Calman - Institute for Family Health - President & Cofounder

There were a couple of things that struck me today. I remember in one of our first discussions, we talked about how sort of privacy and security sort of wrapped around everything we were doing, and I'm coming away from today thinking about how patient and family engagement wraps around everything we're doing because we've literally hit on almost every other part of meaningful use in our discussion today. We talked about outcomes. We've talked about safety. We've talked about privacy and security. We've talked about coordination and in transitions of care. It's like all of it, we kind of talked about the entire spectrum of meaningful use today within the context of the role that patients play in that. And I think that's sort of profound because it shows how fundamental that piece is to the work that we're doing, so that's one thing.

And I think that that sort of ties into what Deven said because, as we think about rolling out kind of the next phases, it doesn't need to stand out there by itself all the time. I think we need to think about the way outcome measures become more important as we're sort of constructing this instead of thinking about, you know, which NQF quality measures are we going to look at. We could think about outcomes in a different frame, more in the way David talked about them. What are the outcomes that are important to patients, and how could we begin to call those out so that we start thinking about that stuff?

I thought that we've sort of constructed these meaningful use criteria with sort of barriers between each of them. And as we're thinking about them more, I think we're sort of feeling like there's one meaningful use piece, and all of this stuff is so intertwined that I think we should start thinking about that as we call these things out, like what is it about outcomes measurement that has more to do with patient engagement and more to do with public health and stuff like that. And really, so that's really one thing I come away with.

The other is that it appears like there's some sort of fundamental elements, and I know I said this before, but I'll emphasize it again that we should just call out right away, and those are universal and immediate access to information. I agree that we shouldn't wait until we figure out exactly what the format is for that or how intelligent it needs to be or whether it's text or structured or whatever. We should just call out that right now people need access to that stuff. I think I really appreciate the point, and I can't recollect who made it at this point, but I really appreciate the point that once people have that information in their hands, a whole set of things are going to start to happen sort of around that, and in that there will be opportunities for people to make that more intelligible, and there'll be a demand on the consumer side to say, you know, stop using these abbreviations. Stop putting it in this format. Give it to me in a way that I can use it better, and probably an industry that will develop around that. That might be very useful. It might add real value to that information.

I guess the last point I'll make is that I was very struck by something that I really have had very little exposure to, which is sort of what the care system is in the home and all of that. And I think we do need to think about that. I don't know whether there's a way to build that into the incentive program that we have, but I think we also have a responsibility to call out things that we've learned that are important that might not be in the current incentive system, and make sure that somewhere the Office of the National Coordinator pays attention to some of that stuff, even if it might not be through the meaningful use objectives.

George Hripcsak - Dept. of Biomedical Informatics Columbia University – Chair

Since we're kind of voting a little bit at the top three, I remember our instant access to information also getting patient's information into ... care, and then the neat idea about the video. Then from here, I can't tell if I'm agreeing or disagreeing with David. I think I'm agreeing with Neil, and you two are agreeing, so mathematically it doesn't work.

What struck me today was more discomfort with quality, NQF quality measurement kind of approach to meaningful use. I'm not even that comfortable on the CMS side for other programs, but for us, more discomfort for us using that and trying to avoid doing that for patient engagement also. And what we really want to have is a quality indicator that says, you know, mortality, satisfaction, and cost. If you could measure that, and that ideally is.... Then you want to promote innovation, and you want to get to the fundamentals, so you kind of create this free market.

Should we have a quality measure for beta-blockers, or should people be crowd sourcing their medical record for them to tell them that they should have been on a beta-blocker? Which thing really gets us further faster? I'm not sure, so I wish we could go to more basic quality indicators. Don't look like NQF things, and then put in stipulations. And I think the best example is that first one, instance access to

information, that will create something on the other end that may be you submit this thing to whomever on the Internet, and they tell you how it's going. Hopefully it won't be so much litigation, but actually advice on how to improve your health.

Paul Tang - Palo Alto Medical Foundation - Internist, VP & CMIO

Art?

Art Davidson - Public Health Informatics at Denver Public Health – Director

Yes. This was an excellent panel, series of panels today. I really want to thank all of you for the effort you put in and the panelists as well. I don't have a lot to add to the comments already made. I just have a few things.

The idea of the video is an important one that we should explore, not only about meaningful use, but the concerns about HIPAA that came up today. How can we communicate better with the populous about this misconception that Neil described. I have my own experience as well similar to that. That shouldn't be happening. If we've voted the top three, the data to the people is right. There's that piece.

Then there was the other piece that Chris Gibbons said this morning about how to use social media better, that there are probably some tools out there that ONC and others could use to really, most effectively get these messages across to the people that we want to be activated to empower.

Earlier, you asked a question, well, if healthcare reform works, and we get the payment right, the elephant is out of the room, is that enough? The typical line that we've been saying for years about HIT, it's necessary but not sufficient. I think that goes for both sides of this. We need healthcare reform, and we need HIT ... I think it was Cris Ross who said something about empowering the patient through these meaningful use measures. I'm not sure that it's one or the other. It's both of them that need to happen, and without the other, we may be less successful with the one that we're targeting right now.

Charlene Underwood - Siemens Medical - Director, Gov. & Industry Affairs

I think you need to communicate that the panel clearly provided an affirmation of a matrix in patient engagement, so I think that was important. And I wanted to follow up and also endorse the flexible approach. One of the things I think we're finding in stage one, especially under patient engagement, because some of those things aren't evidence based, if you will, people are just checking the box. I think, if you can move to a model where they really have to think through patient engagement based on evidence and what they need to do, you're going to move the ball further down the road. So I support the flexibility approach.

Also, I think we heard very strongly that measuring patient experience with the technology, with the encounter, was going to be a good place to start. We heard that numerous times.

One of the barriers, I mean, we've heard the barrier around HIPAA and not understanding is a key barrier. I think another barrier we heard is the crisis in interoperability. I think those two things are going to be tensions to get this going to where we need it to be in terms of enabling patient engagement. Then clearly the overall, at the end of the day, it's really to do this will be the path that gets us to patient centered care.

Jim Figge – NY State DoH – Medical Director

I agree that there are probably two major components to this. The first is input of data and the second is export of data. So with regard to the input of data, I think we need to do this in a very careful way. It needs to be flexible. It needs to take into consideration major public health needs, and it has to be

flexible with respect to the focus of a given clinical practice as well. What are the priorities in the practice, and what are the priorities for the patients in that practice? So I think it's very important that the input of patient generated data is done in a way that's clinically relevant, so that the data comes into a clinical framework or context that actually results in the improvement of patient care.

And we heard some great models presented today, especially Group Health showed us that it's not enough just to collect blood pressure data that's measured at home, but you have to collect it in a clinical system that provides the input from the pharmacist to help the patient manage it, so it's not just enough to collect the data that has to come into the right formwork to do something with the data so that you get the outcomes that you really want. So we're looking for improvement in care, improvement in care coordination, improvement in quality. So I think our thinking about meaningful use has to go beyond just simple metrics, and we have to figure out how to integrate the data collection with the delivery system so that we get the results that we really want.

There are models out there that show us how to do it, so we need to look at the existing evidence base. We should team up with AHRQ and let them do literature reviews for us and get us that evidence they've put together. And then we should advocate for the use of the best models that are out there now, and then advocate for generating more evidence so that we know where to go in the future. So I think that's how we should approach the input of data. Put it into a context that actually gets us the results we want, which is improved care.

Then with respect to the export of data, I think we heard very clearly that all clinical data needs to be transparent. The patient should be able to get his or her data in whatever modality they want it. So if they want it on paper, they want it on a flash drive, they want it in a personal health record, they should be able to dictate that, and they should be able to get it immediately. And I think it's not enough to just give them the raw data. I think the Dartmouth information that we have here shows the value of decision support tools, and I know that there are some free on the Internet, but I think it needs to be pulled into the context of the relationship between the patient and the clinician.

This should be part of the clinical discussion so that maybe Neil's model where the computer screen is right there. The patient is sitting right there, and you plug the relevant data right into that clinical support tool, and you've got the result right there. And then you discuss it, and then the patient can bring that home and do it at home as well. But the clinician needs to use these to interact with the patient. So, again, you need flexibility.

One equation isn't going to work for every practice. Some practices will do this with cancer risk. Other practices will do it with diabetes. So what we've been hearing in New York from providers is that there needs to be more flexibility so that practices can select an area that's relevant to them and their patients, and really work on developing these kinds of tools and support for their patients. So I think that's kind of challenging to figure out how you write that, but that's kind of the concept that I would advocate for.

Paul Tang - Palo Alto Medical Foundation - Internist, VP & CMIO

Good. Thank you. I'll close off maybe with how we started this morning with the hearing, and Regina said it best about the urgent need for non-incremental change, to break the mold of the status quo. I think that is what we heard in panel one throughout. It's basically not later.

And I think Carol also talked about, and I was really impressed, as Neil was, about just visualizing being at home, post discharge. Essentially nowadays patients are kicked out of the hospital, and they absolutely need care that day, the next day, and to see their own provider within the week. And the imagery of just seeing what this HIT tool can help to bring to engage, to educate, not just tell, hand a

sheet, and then to empower was really empowering. And then the whole testing at the end, it's putting into place what we teach to do, but we don't really do. But now we have some tools to be able to do that and bring it to home. That really was impressive. Interestingly, they didn't have the incentive, and they aren't part of the incentive program now, which Neil mentioned as well.

I think, in the end, we as policy influencers and as healthcare professionals need to earn a right to sit at the table to help the patient's health team, and I think, as best we can, we need to try to help move along policies, incentive criteria, etc., that brings us to their table. And this was a tremendous data help ... give us some information and set some goalposts. Thanks to everyone, the panelists, the participants, and the committee. We also have time for public comment.

Judy Sparrow – Office of the National Coordinator – Executive Director

We do. Let me also remind you that we have a blog post going on this topic of patient, consumer engagement. It's on the ONC Web site on the federal advisory page. We do have somebody in the room. Please state your name, organization, and it's a three-minute limit.

Shauna Kass – Kass on Care – President

Shauna Kass. I'm president of Kass on Care. My day job is a health policy and IT strategic consultant, but I want to talk to you as a consumer advocate for 30 years and the cochair of the first federal agency consumer health informatics taskforce back from 1992. We've come a long way. We have a huge way to go, and I wanted to try to speak to some of the near term levers and also the possible, is this unique to HIT or elephant in the room.

I think we've continued to miss the boat, and I hope Christine will be sympathetic to this. Where is our consumer workgroup? We don't have consumers at the table. We have one or two representatives, often a privacy focused advocate. We don't have the diversity of consumers represented in the ongoing policy discussion. And if we don't bring them to the table through a council or at least a sub-workgroup to say here is what works in these very varied and different environments, we're going to continue to be talking to ourselves to a greater degree.

I think absolutely awareness and education campaign that we did fail under HIPAA, and I was in the government as it passed legislation, and then at IBM. And we could perhaps force people to put notices in their offices, you know, or the front of the HIPAA notice, even though we don't read it, necessarily to say you are entitled to your data, and you're entitled to get it in the following ways, as the lead statement, I think, before 2013.

We have, in meaningful use, there hopefully will be flexibility. Everybody has been calling for it in the comments. But with that flexibility, a lot of people will opt out of what is required for patient engagement, and unfortunately we've burdened the provider with the requirement to make the – the individual providers, as opposed to a point of aggregation, at least experimenting with. Providers aren't going to be able to answer the technology questions. They're not going to want to interface with them, except on the clinical aspect. So can we create some models where perhaps all or at least some of the HIEs would be authorized or incented to be that access point as opposed to the five different areas you would have to go if you're dealing with multiple providers. It is potentially going to fail before we get started to provide that access to data.

Then fostering community and state level demos that focus on underserved populations, as well as some of the core groups of providers. Finally, no one has really talked about this, but beware of FDA regulation. It has been in the background for a very long time, and the policy committee already talked

about it. And if that starts up as the approach to how ... facing HIT is overseen, we're going to kill the marketplace. Thank you.

Judy Sparrow – Office of the National Coordinator – Executive Director

We do have one caller on the line please.

Operator

Our question comes from Adita Anaparu.

Adita Anaparu

Yes. Most of the call today has been about the PHR, but.... I've learned a lot of things, and it was really useful. I have first a comment about the interim final rules. One of them refers to timely access, and it very clearly states, it very clearly refers to online access, but it falls short of specifying whether it's referring to a PHR, whether it's any time access, or is it access ... USB or ... drive, or even e-mail it to a patient. That part of it isn't clear. If it is PHR, whether it is referring to ... it needs to be....

The measure that goes along with it is actually a little surprising. It says at least 10% of all ... provider.... It seems a little unreasonable. If the software can actually provide timely access, then they should be able to provide this for 100% of the patients who ask for it. The reason I say ask for it is because software ... make it available ... make the patient's data available to most of services ... Google Health, Microsoft HealthVault. But we cannot influence the patient. We cannot influence the electronic access on the patient.

Both the objective and the measures are a little bit unclear. I do understand that all the decisions that have happened today can go all the way up to stage three, but this is particularly about stage one. Before we get to stage three, we need to get past this. This measure is almost like it's ... being signed up for failing this particular measure. That's all I have to say. Thank you.

Judy Sparrow – Office of the National Coordinator – Executive Director

Thank you. We have one other person in the room.

Alan Vyders – Identity Software Company – President & Founder

Alan Vyders. I'm the president and founder of Identity, a software company, and I'm speaking to you today as a health IT advocate and to not only open the data, but to also open the standards. First of all, the outcome framework, I totally agree. I also totally agree with the idea of uploading and downloading the data. But what we didn't really talk about was actually how you're viewing the data.

For example, a lot of the common standards used in PHRs, CCD and CCR, both of those schemas are not actually accessible to the general public without gaining access to that schema, so really what that's preventing is maybe the grandson, developing a tool to view that data. It's kind of an analogous to saying, here's a PDF, but you can't have the reader. In order to read it, you have to upload it and tether it to some system.

How can you view a CCD or a CCR document right now without an Internet connection? Is there an application that will just view your CCD or your CCR without? I guess what that's showing is that the standard isn't really open. It's kind of open kind of, and that's something that we want to change.

The last thing I'd like to point out is that when we talk about home health data and mobile health data and lack of standards, it's really not all that complicated. For example, blood pressure is three numbers. Blood glucose, very simple, weight, also very simple. So really these aren't hard things to exchange.

Why do we need to necessarily differentiate between machine readable and human readable data? For example, why can't you send blood pressure in by typing it in over an IVR via phone or directly from the device? Or can a person send that in a text message like format? Why can't all of those be the same thing?

There are a few of us companies and interested parties developing a dictionary around that that is performing some of the functionality of continuum, but pointing towards consumer health. It's called OMHE, open mobile health exchange, and it's a micro syntax, but essentially it's a way to send data like weight, blood pressure, mood, over a very short text string, so not having to get into XML and complicated medical informatics. But it's something that a person could actually write. It's just something to think about. Thanks.

Judy Sparrow – Office of the National Coordinator – Executive Director

Thank you. I turn it back to Dr. Tang.

Paul Tang - Palo Alto Medical Foundation - Internist, VP & CMIO

Thanks, everyone. Thank you for coming. Thank you to all the panelist and the committee. See you tomorrow at the HIT Policy Committee. Thanks.

Public Comments Received During the Meeting

1. In response to Paul Tang question about what policy would help: Healthwise, the biggest policy opportunity to advance the consumer's role in effective self-management involves integrating patient-facing decision-support and self-management tools into the workflow of clinicians. 1. The first step would be to add patient-specific education resources as a meaningful use requirement. (And to promote the use of the HL7 Info button standard as an easy way to implement the requirement.) 2. The second step would be to add reimbursement incentives for doctors and for patients who prescribe and use certified self-management and decision support tools. 3. And the third step is to raise the definition of informed consent to a level that requires the use of patient decision aids before major treatment decisions are made. Question for Paul: Palo Alto Medical Foundation has been giving your patients such information for over five years. What problems were encountered and how did you overcome them?

2. Epic has the capability built into their EHR for patients to see their EMR.. Why not require at the policy level for any EHR vendor that has the capability to do this to do so when the providers get it? (Group Health did this)

3. Interoperability requires standardization of data sharing. This should be part of the larger agenda.

4. Thank you for this opportunity to add my comments to those of the distinguished panelists. Given the topic of this hearing it is also important to know that I am a family caregiver and have been for over 25 years. My husband Steven has chronic progressive MS. In addition to being his wife and caregiver, I also serve as his healthcare advocate.

The National Family Caregivers Association (NFCA) is the nation's only organization that reaches out directly to family caregivers, regardless of their loved one's age or diagnoses. We focus on addressing the common issues shared by all family caregivers. Through education, empowerment, and advocacy NFCA works to reduce the disparities between the quality of life of family caregivers and non caregivers. There are more than 65 million family caregivers in America, caring for a loved one with a chronic condition/disability, and they play a critical role in their loved one's care:

- Family caregivers provide 80+% of all long-term care services

- Most care for persons with chronic conditions/disabilities occurs in the community, not in institutions
- Thirty nine percent of seniors take a visit companion (most often a family member) to their doctors' appointments. Sixty four percent participate actively.
- Half (52%) of the family caregivers who care for adults serve as their advocates with medical professionals and paraprofessionals, insurers, government, etc.
- Twenty two percent perform medical or allied medical tasks
- Over 40% manage medications
- Half of all family caregivers age 65+ provides all of their relative/friend's care.

If for no other reasons than the facts just cited, primary family caregivers (and their loved ones, when able) need to be woven into the fabric of the meaningful use final rule, have access to EHR and be actively engaged in conversation and discussion with their care recipients' providers. It would be completely irresponsible to lock out of the information loop the two people, who are the only individuals consistent across all settings of care and most familiar with the day-to-day changes in a patient's condition.

My recommendations to the committee regarding the rules governing meaningful use of health IT are:

- Begin with creating a definition of meaningful use that answers the questions – meaningful to whom and usable by whom.
- Recognize and build into the rule that persons with chronic conditions require more access and engagement than patients who are inherently healthy.
- Mandate that patients and their primary family caregivers be included in the care team and provide them with the education and tools they need to participate as actively as they would like.
- Mandate that patients and their primary family caregiver have access to all EHRs whenever they want
- Present information in ways that patients and caregivers can easily understand – engage patients and families in determining what those ways are
- Engage patients and family caregivers in electronic dialogue and transference of information, both data and narrative
- Pay relevant healthcare professionals appropriately for the time and expertise they bring to the engagement process

Thank you for your time. The meaningful use rule is vitally important to NFCA, its members and other constituents.